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STROKE CARE MAPPING:
A STUDY OF THE DEVELOPMENT AND APPLICATION OF THE DEMENTIA CARE MAPPING TOOL IN STROKE CARE

A PORTFOLIO OF RESEARCH, PRACTICE AND STUDY

Submitted in fulfilment of the
requirements for the degree of
Doctor of Clinical Psychology (DClinPsych)

VOLUME 1

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VOLUME 1

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SECTION A: PREFACE

PREFACE

When I first qualified as a Clinical Psychologist I worked in mental health and began to develop a special interest in working with older adults. As my career developed I began to focus specific interests in the fields of dementia and more recently rehabilitation for individuals who have received a brain injury, either via a stroke or head injury. My experience in working across different specialisms suggested to me a tendency amongst Clinical Psychologists to become easily compartmentalised, with a narrow focus in their specific area of work whether that be for example in the care of the elderly, rehabilitation or learning disability and there was little cross fertilisation of ideas. This research has given me the opportunity to seek to prove that one area of work has much to offer another, in that my knowledge and experience in dementia care can be applied to the field of stroke rehabilitation.

Within stroke rehabilitation, which has emerged from a very strong medical tradition, there can so easily be an over emphasis on the physical capability of individuals who have had a stroke, and scant attention has often been paid to the person in this process and how their well-being in a hospital environment may of itself influence rehabilitation outcome. Professor Tom Kitwood and Dr. Kathleen Bredin (1992) tackled similar issues in the treatment of individuals with dementia in care settings and introduced the concept of person-centred care through the development of the Dementia Care Mapping method as a means of measuring the quality of care in terms of the experience of the person. The focus of the current research is to examine the applicability of Dementia Care Mapping in the area of stroke care and to evaluate whether Stroke Care Mapping can make a contribution to stroke rehabilitation. Whilst carrying out an analysis of the process of rehabilitation, discourse analysis is also employed to provide a more in-depth view of staff/patient interactions and to determine whether this could be incorporated as an additional component of Stroke Care Mapping.

Another vital aim of the current research is to ascertain whether this tool has value not only to assess person centred care but also as a means of being an agent of change. Therefore a training intervention for ward staff is structured using the results of the Stroke Care Mapping and the principles of person-centred care, and a re-evaluation is subsequently carried out on the ward.

Section C, which involves case work, is also related to the field of rehabilitation and yet is different in emphasis from Section B. In Section B, my work as a clinician is seen as facilitating person-centred care and involves working at the macro level of the ward with cultural change which has at its core a strong training component. However, in Section C the emphasis is on case work and illustrates how innovation can help with individual client work for those with memory problems. In this Section a case study evaluation of mobile phones as a new external memory aid develops an idea presented at the Headway conference in Nottingham in 1997 by Dr Jonathan Evans, who, together with Wilson, Emslie and Malinek (in press), evaluated the 'NeuroPage'. This idea was originally developed by Hersh and Treadgold (1994) and offered individuals with memory impairments the use of an external memory aid in the form of a pager. My interest was to see if this idea could be developed into the domain of mobile phones, so that individuals could receive a call on their mobile phone at a particular time with recorded messages to serve as memory prompts for whatever information had been mutually decided upon with the receiver. This study represents an example of how networking can be used creatively to work in the interests of those individuals with a brain injury who have a memory impairment. The study required liasing with a computer company to provide the software which would be necessary to provide messages on a mobile phone at specific times and negotiating with Jersey Telecoms to provide the mobile phones free of charge for those individuals interested in taking part but did not possess a mobile phone. The research demonstrates the potential of this area of work and makes recommendations for future use of this external memory aid.

Another illustration about the value of cross-fertilisation of ideas from area to area of Clinical Psychology is the recent approval from a drug company to fund a trial of mobile telephones as a prompting system for individuals diagnosed with mild dementia.

By contrast to Section C the last section provides an illustration of the amount of theoretical knowledge required in a specific area of neuropsychology. The literature review in Section D gave me an opportunity to review the assessment and treatment of executive function impairments. This area of neuropsychology interests me greatly because the type and nature of problems that individuals with executive function difficulties are often overlooked and yet their effects on the individual can be devastating in a day to day context.

Therefore, in my opinion a sound understanding of this area should be a fundamental prerequisite to anyone working in the area of brain injury.

The review begins by looking at the neuroanatomy and assessment of the frontal lobes followed by a critique of standard neuropsychological assessments. What is meant by 'executive functioning' is examined in further detail and the models which have been developed to explain this collection of symptoms are described. The review examines what can be done to re-mediate these difficulties, although the literature is still patchy. The conclusion recommends a flexibility in approach to executive functioning impairment, an aspect of our cognitive functioning which spans across and influences almost every second of our waking day.

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Kitwood T., & Bredin K. (1992) A new approach to the Evaluation of Dementia Care. Journal of Advances in Health and Nursing Care 1(15): 41-60.

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SECTION B: RESEARCH

STROKE CARE MAPPING: A STUDY OF THE DEVELOPMENT AND APPLICATION OF THE DEMENTIA CARE MAPPING TOOL IN STROKE CARE

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ABSTRACT

This research aims to measure the process of rehabilitation from the individual perspective by adapting Dementia Care Mapping (Kitwood and Bredin 1992) and applying it to the area of stroke rehabilitation, which is referred to as Stroke Care Mapping (SCM). SCM was carried out on a rehabilitation ward with 8 participants who had suffered a stroke. Mapping took place during the course of a typical day from 9.00am to 4.00pm. Results showed that individuals spent some 42% of their time on their own without any accompanying activity. There were also some 35 examples of Personal Detractions, which represent specific incidences where care is not person-centred.

Conversations between staff members and these participants on the ward, in the dining room and in therapy sessions were recorded onto a cassette in a variety of contexts. The audio tapes were analysed using Discourse Analysis to shed more light on the actual process of care. The results showed that on the ward and in the dining room participants spent a great deal of time in silence. Types of interactions between staff/patient comprised mainly of simple explanations and questions which require a yes/no response. However, interactions with the therapists were more likely to be reassuring and sociable than with nurses with a greater emphasis on explanation, teaching and encouragement.

The results of the SCM and Discourse Analysis were used to form the basis of a person-centred training programme for staff and SCM was used as a before (SCM 1) and after measure (SCM 2). During SCM 2, six out of the original 8 participants were mapped (2 participants had been discharged). Comparison of SCM before and after the training showed an elimination of Personal Detractions in SCM 2 and participants only spent 34% of the time on their own with no accompanying activity. The amount of conversations between nurses and between patients increased for participants in SCM 2 and these interactions received a higher overall care value than during SCM 1. The Care Values between SCM 1 and SCM 2 only showed a slight positive increase for the majority of participants. A number of positive changes were made on the ward as a result of the SCM, such as the increased use of group work with individuals from the ward.

These findings suggest the amended version of Dementia Care Mapping has some potential in the area of stroke rehabilitation to offer an insight into the experiences of patients on a stroke ward. Discourse Analysis of taped conversations provided in-depth qualitative information about the process of care but its use as an adjunct to the SCM tool is limited because of the time consuming nature of transcribing the conversations. Increased use of the SCM method, over the course of the research, led to the development of a number of improvements on the ward, the most significant of which includes the mapping of activity directed towards a person's rehabilitation goals.

Recommendations for the future include further use of SCM and the collection of comparative data from other rehabilitation settings. SCM has potential in rehabilitation not only to measure the quality of care from the perspective of the person with a stroke but also as a potential agent of organisational and cultural change.

CHAPTER 1

STROKE CARE MAPPING:

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1.0 Introduction

Stroke is one of the major maiming diseases in our society today and treatment presently accounts for some 5% of the total NHS budget. It is anticipated there will be an increase of up to one third in first ever stroke sufferers by the first quarter of the next century (Malmgren et al. 1989), which means there will be a marked increase in the need for acute care and early rehabilitation services. Despite this obvious importance, rehabilitation services in this area remain fragmented, haphazard and sub-optimal (Lindley et al. 1995). Even though stroke has been singled out as a key area for attention in the United Kingdom Government's strategy for health (Health of the Nation, Dept of Health 1992), the majority of rehabilitation work is focussed on enhancing physical recovery, and hospital treatment is still entrenched in a medical model of operation which pays little attention to the person in the rehabilitation process. The effects of the social and therapeutic environment of the ward on the individual and how this can affect rehabilitation outcome have been largely ignored, yet the quality of the rehabilitation environment form the position of the patient in psychological terms is of great importance in the process of recovery. Therefore, qualitative research to evaluate a rehabilitation environment in a hospital setting which has as its emphasis the person in the process of care is of paramount importance.

Many variables interact together on a stroke rehabilitation ward to make up the ingredients of a therapeutic environment: the complex interplay of individual characteristics, experience and training of staff, framed within the social backdrop of cultural values and norms, coupled with the personality, motivation and expectations of patients, all play a vital role in providing the social context of rehabilitation. This therapeutic milieu will not only affect the process of care on a day to day basis, but will also influence the quality of care, which in turn can have a significant effect on an individual who has had a stroke and on their rehabilitation outcome. The present research examines whether the experience of an individual can be captured and measured by means of an assessment tool so as to provide an effective qualitative assessment of the rehabilitation experience from the point of view of the patient, and to seek to apply the lessons learned to improve that experience.

Before examining these research possibilities further, a preliminary review of the area of stroke rehabilitation is provided, and the meaning of the work 'stroke' is explored, along with the evolution of the rehabilitation approach to disability. An overview of present services is given, along with a description of the key professionals involved in the work of rehabilitation through the multi-disciplinary team. Moving away from the medical model of operation, the psychosocial context of rehabilitation is considered to examine what variables have an influence on the rehabilitation environment and to what extent these variables are likely to affect an individual's experience. In order to do this an analysis of the individual is set within the social context of rehabilitation with a consideration of the social model of disability and our attitudes before exploring the dynamics of the staff-patient relationship. Particular attention is paid to the nature of this relationship because the emphasis of this research is on how such relationships can influence a person's experience and the quality of that experience, which may ultimately affect that person's rehabilitation outcome and adjustment to disability.

1.1 Definition of Stroke

'Stroke' is a general term that is widely used to encompass a whole variety of symptoms and severity of impact for an individual. The World Health Organisation has defined it as 'rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin' (Aho et al. 1986). Its definition typically includes subarachoid haemorrhages but excludes transient ischaemic attacks (TIA), subdural haematomas, silent cerebral infarcts and haemorrhage or infarction caused by infection or tumour. The majority of strokes involve cerebral infarction but intracerebral haemorrhage (excluding subarachoid haemorrhage) accounts for just over 10% of all strokes. (Ricci et al. 1991, Bamford et al. 1988).

To portray the varying symptoms and levels of difficulty associated with stroke the classification system of 'impairment', 'disability' and 'handicap' used by the World Health Organisation (1980) can be employed. 'Impairments' are usually the external manifestations of the pathology - the symptoms and signs - which may be varied and complex e.g. paralysis of one side of the body, loss of speech and the power to communicate, swallowing difficulties, incontinence, cognitive difficulties (visual, perceptual, memory, orientation) balance problems, depression and changes in personality. 'Disability' refers to changes in the interactions between the patient and the environment, and these altered behaviours can occur in any domain of life and range from incontinence to activities of daily living to interactions with other people. Many of the disabilities mentioned can have a lasting effect and result in a change in social position which arises from illness which refers to the social, societal and personal consequences of the disease and have been termed the 'handicap'. To provide some examples of the range of altered behaviours individuals can experience after a stroke in the acute phase and up to six months later the following table provides some useful information:

Table 1: Figures per 100,000 population (Wade 1994)

Impairment/disability presentation (need acute care)	**Number per 100,000 population**
With reduced consciousness	84
Severely Dependent	140
Incontinent of urine	106
Disorientated/unable to communicate	132
Unable to get out of bed unaided	168
Impairment/disability at three weeks (needs rehabilitation)	
Needs help dressing	86
Needs help walking	67
Needs help with toilet	66
Communication problems	49
Impairment /disability at 6 months	
Needs help bathing	71
Needs help walking	22
Needs help dressing	45
Difficulty communicating e.g(aphasia)	22
Confused/demented (+severe aphasia)	39
Severely disabled (Barthel ,10/20)	13
Services - at 6 months	
Needs long-term institutional care	23
Possibly needs speech therapy	24

The above Table shows that during the acute phase many individuals are very dependent - about 40% of patients will have a reduced level of consciousness in the first 24 hours, and about 80% of individuals will developed a hemiparesis (Herman et al. 1982). Improvements are made over time, but for many there are some lasting aspects of their disability. This table makes some reference to communication problems and confusion, but does not include the vast array of cognitive problems that can present themselves following a stroke, nor the possible debilitating effects of mood changes.

Given that stroke varies so markedly from person to person, there have been many attempts to break the term down into various classifications. However, even though the severity of stroke is of clinical relevance for the management of individual patients and in predicting outcome in populations, there are no widely used categorisation tools. Although research work continues in the area of classification (Bamford et al. 1991, Ricci et al. 1993) and there are some promising developments for the future, most hospital medical notes still appear to continue to use the term 'stroke' along with a description of the nature a particular patient's difficulties.

1.1.1 Incidence

Stroke is the most common cause of adult disability in the UK (Martin 1988), and since stroke rates increase greatly with age and the number of elderly people is increasing, the burden on society of stroke is certain to rise. Many attempts have been made to examine the incidence of stroke, but most studies have been beset with significant methodological flaws.

The Oxford Community Stroke Project (OCSP) is the only study in the United Kingdom to fulfil the criteria outlined by Malmgren et al. (1987) for an ideal register. However, it should be remembered firstly that this study was commenced some 17 years ago when mortality rates were higher, and secondly that the study area was predominantly in rural Oxfordshire with no ethnic minority groups. This study found that the overall incidence of first-in-a-lifetime stroke is 2.4 per 1000 per year. Incidence rates by age show that the likelihood of having a stroke increases with age: rates per 1,000 per year are roughly 0.57 for both males and females between the ages of 45-54 but this increases to 6.90 for between the ages 65-74. However, over 20% of victims are still under 65 years of age (Bamford et al. 1988). The lifetime risk of having an acute stroke is higher in men than women; however, the converse is true for the lifetime risk of dying of a stroke - approximately 16% of all women are likely to die of a stroke compared with only 8% of men. This difference is largely attributable to the higher mean age of stroke onset in women and to their greater life expectancy. Mortality rates vary (Bonita 1992), but stroke has been identified as the third most common cause of death in the United Kingdom.

1.1.2 Prevalence of stroke

There is a lack of information on the prevalence of stroke in terms of the number of stroke sufferers in the population. Prevalence rates have been estimated using the incidence and survival data from stroke registers, but there have been few studies. In Australia it was estimated there are 5-8 stroke sufferers per 1000 population over the age of 25 years (Christie 1981). It has been estimated that in England the number in the community with stroke at any one time is approximately 500-700 per 100,000 (Wade 1992). A more recent study carried out by Hillman et al. (1995) has reported preliminary findings from a survey, by means of a postal questionnaire, of stroke survivors in Nottinghamshire from which a total prevalence rate of 46.8 per 10,000 population was estimated.

1.2 The development of rehabilitation services

For those individuals who have passed through the acute phase of having a stroke, rehabilitation services have developed enormously over the last 50 years. The origin of this approach lie in a number of separate developments since the 1st world war. This war saw the development of military orthopaedic hospitals which were established to treat casualities and help them return to active service (Mattingley 1981). World war II again meant that a large number of wounded personnel needed help to return to work (Clarke 1987). The need for prosthetic services increased markedly during the wars, which led to the development of physiotherapy and occupational services, and many of those who worked in these areas carried their skills and interests into the civilian sector; so rehabilitation services began to develop. The polio epidemic of the early 1950's saw the emergence of rehabilitation departments and the crucial change in emphasis from convalescence to rehabilitation as a means of helping an individual to recover (Squires 1996).

1.3 Towards a definition of rehabilitation

The term “rehabilitation” has a wide meaning and can be applied to many different things: convicted criminals, recovering alcoholics and soldiers injured in action. It is recognised that there are many definitions of rehabilitation and that no single definition is universally accepted. Indeed, it could be proposed that rehabilitation is too complex a concept, process or activity to define to the satisfaction of all agencies. However, a useful description of the role of rehabilitation has been put forward by Wade (1992) who states that:

‘Rehabilitation should aim to maximise the patient’s role fulfilment and independence in his/her environment, all within the limitations imposed by the underlying pathology and impairments and by the availability of resources. This helps the person to make the best adaptation possible to any difference between roles achieved and roles desired’.

The 1998 proposed ICDH (International Classification of Impairments Disabilities and Handicaps) model views rehabilitation as a set of influences, procedures and resources applied to the disabled person and the environment. Rehabilitation is seen as a problem-solving educational process focusing on the concepts of ‘impairment’, ‘disability’ and ‘handicap’ (which have not, as yet, received universal approval). This definition embodies the whole process of facilitating the restoration of a person with a disability to optimum functioning (physically, socially and psychologically) to the level they are able or motivated to achieve. However this model continues to have a medical emphasis, and is heavily criticised by those who support the model of social disability, as distinct from physical disability, which is discussed later.

1.4 The provision of stroke services

The development of units providing stroke rehabilitation led to a debate about the location and nature of rehabilitation services. The Tunbridge Committee argued in 1972 for the creation of a medical speciality based on physical medicine to be the focus of new rehabilitation departments at district general hospitals. However, this proposal was initially resisted by other specialities such as geriatrics or psychiatry who saw it as a threat to their power base. Despite such opposition the speciality of rehabilitation medicine has emerged, but tension remains as to whether it should be an integral part of mainstream services or a speciality in its own right (British Geriatric Society 1997). These inner tensions have led to wide variations between and within hospitals in the types of services that stroke patients receive. As a result there is a considerable variation in stroke services within the UK, many of which are poorly tailored to the needs of patients (Kings Fund Consensus Statement 1988, Lindley et al.1995, Wade 1994).

There is also a marked geographical inequity in the quality of rehabilitation in that the nature of the service received will depend on the admitting hospital. Lindley et al. (1995) found that 67% of physicians indicated that they routinely cared for patients with acute stroke and around 40% of patients were treated by geriatricians. Only 5% had access to an acute stroke unit and less than half had access to a specialised stroke rehabilitation unit. Although stroke care usually involves hospitalisation, wide variations have been reported. These fluctuations have been found to vary enormously (Wade et al. 1985) and range from 50 to 90%. These national incongruencies have emerged not only because of the varying power bases within hospital regions for this speciality but also because of the shortage of evidence about which pattern of services is the most effective (Beech 1996). However, where stroke rehabilitation services are available there are two main types of unit: one for the acute phase and another for the more longer term rehabilitation of stroke.

1.4.1 Acute Stroke Units

Acute stroke units provide intensive care for stroke in the acute phase which generally lasts for a few days. By one week post stroke the situation is usually stabilised, at which point the acute and rehabilitation phases merge. There have been several non-randomised studies of acute stroke units (Pitner and Mance 1973, Kennedy et al. 1970, Drake et al. 1973) but none has so far shown that they improve outcome. A recent review paper proposes that there is little evidence that any form of acute intervention after stroke produces significant benefit, except for a small subgroup (Rudd 1996).

1.4.2 Stroke Units

The primary purpose of a stroke unit is to provide stroke rehabilitation. The aims of stroke rehabilitation have been defined by the WHO: to aid physical recovery from stroke; to promote physical, psychological and social adaptation to stroke-related disability and handicap; to encourage a return to independence and activities of daily living; and to prevent secondary complications of stroke and related conditions, such as pneumonia and depressive illness.

The meta-analysis of 10 trials of stroke units (Langhorne et al. 1993) clearly showed that organised care for stroke produces better results than disorganised care. A reduction of 28% was demonstrated in in-patient mortality in the groups managed on a stroke unit and this difference was still present when the one-year mortality statistics were analysed. Indeed, a recent study in Denmark (Jorgensen et al. 1995) showed benefits across the range including a reduction in mortality, length of hospital stay, frequency of discharge to nursing homes and cost. However, comprehensive detailed evidence is not yet available as to what happens on a stroke unit. Whatever provision in service there is for an individual who has suffered a stroke, the work of the staff who are responsible for providing rehabilitation services, and the quality of that work, is of paramount importance in this field.

1.5 Professional involvement in stroke rehabilitation

Rehabilitation is a continuous multifactorial process which is often dependent on multiple inputs. Because a whole range of skills and expertise is needed it is not usually possible for one individual to cover the whole spectrum comprised in rehabilitation, and therefore a team approach is needed. A multi-disciplinary team approach is utilised in the delivery of care in a rehabilitation unit, and the type of professionals that are involved varies enormously throughout England, Scotland and Wales. However, a team will typically comprise of medical representation, nursing, occupational therapy, physiotherapy, speech therapy and occasionally the input of social work and clinical psychology. Each discipline has its own theoretical framework, tradition, sense of mission, priorities and rules. The role and function of the various professions involved in rehabilitation can be described below:

1.5.1 Medical services

Rehabilitation is seen as an integral part of the work of geriatricians, neurologists and other medical professionals specifically dealing with both acute and long term medical conditions. Nurses have always played an important role in specialist rehabilitation units (Sheppard 1994). The nursing literature identifies the nursing role in stroke as the maintenance of hygiene, in particular maintaining the integrity of the skin, bowels and bladder; the organisation and co-ordination of care on a 24 hour day to day basis; the continuation of therapy; and patient/carer education, support and counselling (Myco 1984, O'Connor 1993, Waters 1994). Whilst this fits easily into the pattern of care in the acute stage of stroke, there are difficulties with nurses having such a defined role when it comes to rehabilitation. Indeed, there has been an increasing recognition of the need to redefine the nursing role in rehabilitation, particularly in multi-disciplinary teams for older people (Ford 1991) and to develop a core of rehabilitation skills in nursing, in addition to those which are predominantly organisational (Wild 1994). These core practise rehabilitation skills, which can be identified as physiotherapy, speech and language therapy and occupational therapy, should be viewed not so much as the addition of new skills but the enhancement of those which already exist, and which should be in operation throughout the stroke patient's day. This maintenance role for nurses in rehabilitation, which proposes a process whereby nurses can enable patients to practise what they learn with the therapists, has also been advocated by Henderson (1980) and

Mayer (1991). However, research in the area shows that the daily reality of the work of nurses, and their attitudes to rehabilitation, do not always reach this ideal (Irwin 1996).

1.5.2 Professions Allied to Medicine

Therapists (including Physiotherapists, Occupational Therapists and Speech and Language Therapists) play a key role in rehabilitation in both hospital and community settings. A primary aim of Physiotherapy is to enhance mobility and physical independence and is regarded by many stroke survivors as the most important form of treatment they received (Pound et al. 1994). However, the level of faith in physiotherapy is not matched by scientific evidence of efficacy (Tyson 1995).

Occupational Therapy involves the treatment of physical or psychiatric conditions facilitating patients' continued participation in daily activities (Mackay and Rudd 1996) in order to help people reach their maximum level of function and independence. Some 97% of stroke patients receive Occupational Therapy on a stroke unit as compared with 60% of those treated on a medical unit (Smith et al. 1982). Many services concentrate on assessment of activities of daily living and adaptations to the environment (Smith 1989). However, cognitive and perceptual assessment are also beginning to be carried out more frequently. In addition, Occupational Therapists are spending more time helping to plan the safe discharge of stroke patients, and in the UK they have become the key players in the assessment of the home environment and the provision of equipment to aid independence. As with physiotherapy, occupational therapy has also developed many different styles of practice which have evolved more though intuition and clinical experience than scientific research (Mackay and Rudd 1996).

One of the main aims of an intervention for the Speech and Language Therapist revolves around reducing linguistic impairment and disability through detailed assessment and treatment of specific areas of language breakdown. Therapists also work towards educating carers to maximise communicative potential and supporting them in the consequences of their disability. Where necessary, alternative communication strategies are developed (Quinn and Campbell 1996).

1.5.3 Other members of Multi-Disciplinary Team

Social Workers can be involved in the rehabilitation team. However, social work is concerned with maintenance and support to enable people to lead preferred lifestyles, it can also aid independence and encourage learning. In some places the social worker plays a part in hospital discharge arrangements. Rehabilitation is not generally seen as part of social work and social workers potential input into rehabilitation may remain untapped.

There are few Clinical Psychologists involved in working with stroke patients in the United Kingdom, whether in hospital or in the community. Generally speaking, the work of those Clinical Psychologists in stroke rehabilitation involves facilitating patients' and carers' adjustments to the longer term social and psychological impact of stroke by providing psychotherapy. In addition, a crucial component includes multidisciplinary staff training with regard to psychological aspects of stroke disease, and counselling. Many Clinical Psychologists become involved in neuropsychological assessment of cognitive difficulties following a stroke and assisting in the development of cognitive rehabilitation packages. All of the various professionals involved with the person on a rehabilitation unit often work together in a multi-disciplinary team.

1.5.4 The work of the Multi-Disciplinary Team

In this context ‘multi-disciplinary’ implies that each member of the team operates within the boundaries of the objectives and competencies adopted by his/her own profession. The multi-disciplinary team becomes involved in a number of processes in an ideal rehabilitation setting. Most of the time spent by the various professionals will be in activities in their own specialised areas. When a person first comes into a rehabilitation ward the various professionals generally undertake an assessment which involves the collection and interpretation of information relevant to their own speciality. There also needs to be a significant amount of time spent in sharing this information so that all team members know what other members are doing, so formal meetings are essential. There are often two types of patient- orientated meetings. The first is the brief, often daily, meeting where the team of professionals discuss problems that have arisen, which is sometimes referred to as a ‘handover’ meeting and does not always involve the therapy staff. The second type of meeting is the patient care/case conference which tends to be more formal and often involves documentation. The patient conference can be used as a initial goal setting opportunity or a ‘discharge planning meeting’. The latter often involves the patient, carer/s and relevant family members who look towards discharge, distant goals, and follow up arrangements.

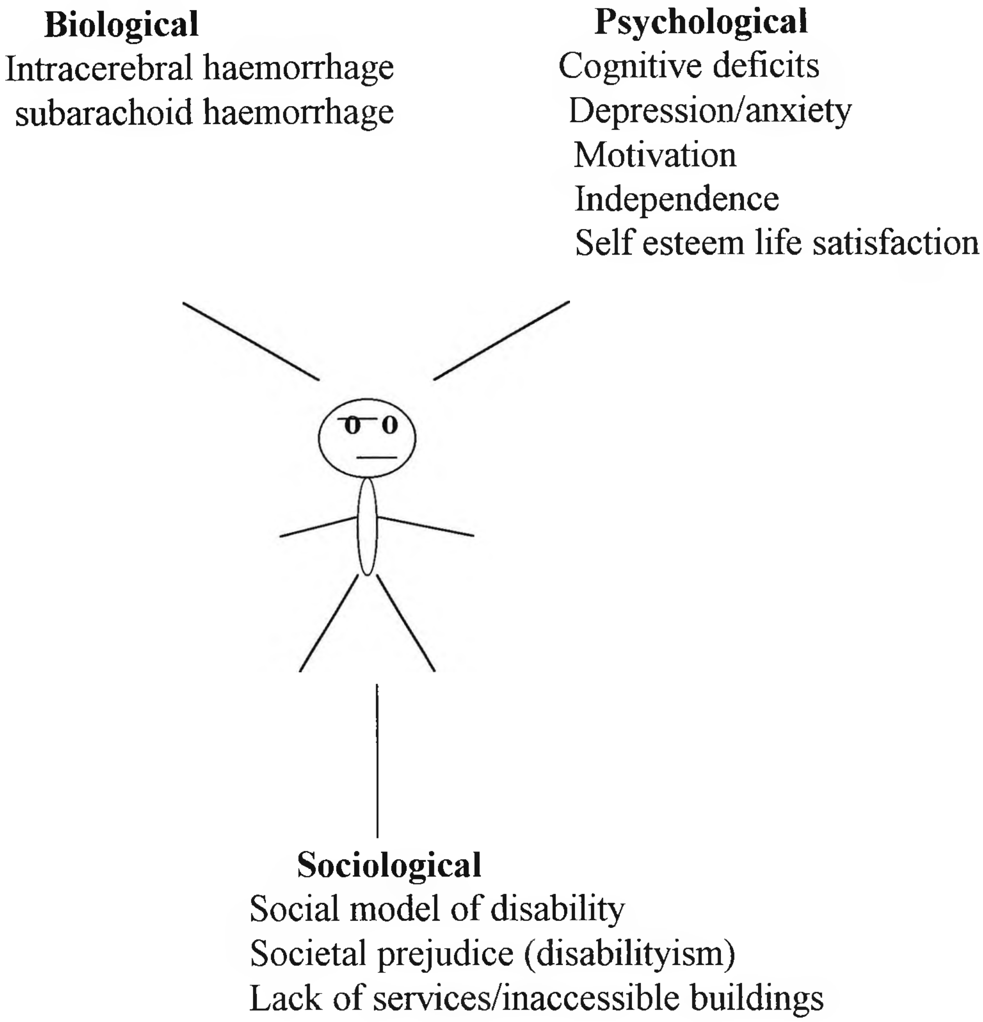
One of the most common ways of co-ordinating the focus of teamwork is to appoint a keyworker, whose responsibility it is to ensure a thorough knowledge of the patient and to make sure that progress is monitored and reviewed. It many instances, the keyworker also takes on an advocacy role for the patient. Some rehabilitation units have a less developed system than this, and rather than operate keyworkers a named nurse is appointed who has a similar role but the focus tends to be on nursing duties.

The multi-disciplinary team often sets goals for an individual during their time in rehabilitation. However, the setting up and evaluation of goals is another primary purpose of rehabilitation, and this can often be one of the most overlooked aspects of a persons time spent in rehabilitation. Goal setting should be carried out following a careful assessment, by professionals, of the patient and should ideally precede all rehabilitation interventions. Young (1996) states that successful goals should be meaningful, in that they are appropriate to the problems and circumstances of the patients. Rehabilitation goals need to be agreed through consultation and negotiation with the patients, caregivers and the rehabilitation team and should be clearly communicated and realistic. In setting goals it is important to make sure they are not vague statements but are precise and unambiguous along with a clear identification about who will do what, under what conditions and to what degree of success. Lastly, interventions can conceptually be divided into treatments, which are intended to affect change and ultimately lead to improvements in the patient.

1.6 The psychosocial context of stroke rehabilitation

Stroke rehabilitation has strong medical roots which have influenced its development and operation and as a consequence of this little attention has been paid to the importance of psychosocial aspects in this area. There are a whole range of influences which can affect an individual with a disability and these can be described diagrammatically by presenting the complex biopsychosocial process of rehabilitation (Kemp 1990):

Figure 1: Diagram to illustrate the biopsychosocial process of rehabilitation:



Each of these range of influences are vitally important and need to be examined in further detail with particular emphasis on the psychological and social context of rehabilitation.

1.7 The Psychological Context

The onset of a severe disability is possibly one of the most life changing events that can happen to someone in terms of its impact on daily life. It can have far reaching implications for the future and may mean that a person has to use adaptations for the rest of his or her life. The changes most often experienced include: a decrease in daily living skills and social independence which can have a significant impact on sources of life satisfaction and self esteem. Adapting to these changes have been found to cause even more stress than the death of a spouse (Blazer and Williams 1980).

1.7.1 Perceptions of illness and adjustment

A person's psychological reaction to his or her stroke is of crucial importance in determining rehabilitation outcome and has the potential to influence an individual's success in living with a disability. The process of coming to terms with a stroke has been likened to a number of distinct responses which have been identified during the bereavement period after loss or death of a partner (Parkes 1972). The acute phase of the adjustment process includes what others usually term the shock and denial phase (Athelstan 1981). During this phase the person may not be functioning very well intellectually or emotionally because the shock of the event and its potential implication may overwhelm his or her coping capacity. The nature of the onset and the perceived implications of the illness are two factors that will determine the response at this point. For a stroke the onset is usually very sudden, a person can be sailing a boat one minute and the next they wake up on a hospital ward paralysed by a stroke. After the person has got over the initial shock, a whole range of emotions can be experienced. The second phase centres around the theme of acknowledgement and reorganisation. Some of the most important tasks at this stage are for the person to deal with any emotional problems, recover from the stroke and find alternative ways of maintaining life satisfaction. This phase is marked by the establishment of a regular program of improvement and the routinisation of care. The family's task at this stage changes from arranging life sustaining and acute care support to fostering independence (Kemp 1990). All of these reactions are thought to occur in the normal process of loss and grieving before a successful adjustment to the trauma is achieved. The period of adjustment and adaptation varies in time as a function of the nature of the loss and its significance for the individual, although much research remains to be done in this area.

It has been claimed that loss is a universal experience common to all disabled people across all disabilities which involves the individual and their families passing through various phases before they are 'able to gradually integrate the reality of the situation' (Berger 1988). It is likely that these conclusions have been reached by the 'able bodied' in society who assume that to become disabled involves a tragedy and therefore a process of bereavement would naturally ensue. However, there have been a number of studies which demonstrate that not all disabled people experience their disabilities as loss (Campling 1981, Sutherland 1981, Oliver et al. 1988, Morris 1989). Further there is little support for stage theories so far as disabled individuals (Trieschman 1980) or families (Vargo and Stewin 1984) are concerned. Withers (1996) quotes a example of a young girl who seriously damaged her knee and stated that she faced “the prospect of no more gym or bike riding” with equanimity, but when it came to facing an anaesthetic she experienced chronic anxiety. Withers (1996) feels that non-disabled counsellors tend to project the feelings they imagine they would have in the disabled client’s position.

It is important to emphasise that each person’s experience of disability will be idiosyncratic depending on; their personality, their belief systems along with cultural and social factors, age and position in the life cycle. However, the most common problems experienced are depression, anxiety and somatisation. A range of studies have indicated that depressed mood and more frequently depressive symptoms are highly prevalent after stroke and occur in 20% to 60% of patients (Reich 1996). The mechanisms underlying successful adjustments by patients and their carers to a life-threatening illness, such as stroke, are as yet minimally researched or understood.

The cognitive aspects of coping with health concerns have been addressed by models such as the Health Belief Model (Rosenstock 1966, Becker 1979) and the Theory of Reasoned Action (Azjen and Fishbein 1980). However, these models which attempt to examine the impact of beliefs on coping tend to be weak predictors of behaviour on their own, and Ingham (1994) has suggested that it is because the information to support them is typically collected by questionnaire, thus forcing responses into predetermined categories and ignoring powerful variables such as contextual factors. It may be profitable to look beyond these rational models of human behaviour and focus on the symbolic meanings of illness because it is the meaning we place on events, including disability, which governs our response to them (Barnlund 1978). The importance of what meaning a person attaches to illness has been explored by Lipowski (1970) who identified eight individual personal meanings of illness which can be construed as; a challenge, an enemy, a punishment, a weakness, a relief, a strategy, a loss, a damage or a value. The issue of 'controllability' was added to this original list by Schussler (1992). It is vital that professionals should acknowledge and understand these meanings to be effective agents in therapy.

In terms of adjustment to disability some researchers have focussed on the work of Rotter (1966) in his development of the concept of locus of control. In a study of stroke and orthopaedic patients, patients with an internal locus of control (regarding themselves as being able to influence the course and progress of their illness) have a better prognosis in terms of functional outcome than patients with similar levels of disability, who identify chance factors or other people, such as doctors, as determining their recovery. An internal locus of control in these circumstances may mean that individuals work harder on their rehabilitation because they are of the opinion that they can have an influence on the final result. This may also mean that they are more motivated and their efforts have a positive effect on both patient and health professional alike. Partridge and Johnston (1989) in a study of locus of control for recently disabled adults also found that patients with a greater internal locus showed a speedier recovery.

A successful search for the cause and meaning of a stroke has also been significantly associated with better psychological adjustment (Thompson 1991). Others have suggested that pre-morbid dispositional style such as optimism (Sheier and Carver 1985) or Type A behaviour patterns (Shima et al.1994) may determine the interpretation of one's situation and eventual adjustment in patients.

1.7.2 Becoming a Patient

Patients who enter a rehabilitation ward are often vulnerable because they are entering into a world of which they have no experience. They are becoming involved with many professionals and are embarking on relationships that are unusual in many respects. The professional often asks intimate questions and encroach on personal space in a way that would be intolerable in almost any other social situation. Patients must find ways to deal with this discomfort and an important aspect of the professionals role is to minimise discomfort. Failure to address this problem may be one of the antecedents of passive compliance or learned helplessness as coined by Seligman (1975) or indeed, in some cases this may amount to non-compliance. The personal qualities of the professional have been identified as one of the 'predictors' of compliance along with the severity of illness as perceived by the patient and their cultural beliefs (Brannon and Feist 1992).

The individual which has been recently admitted to a ward, has to add the title 'patient' to the list of roles by which he or she is identified and this will involve a struggle at many levels in the process of attempting to adjust to significant life changes. The disability causing these changes may bring pain, disfigurement, increasing limitation of movement, increasing physical dependence and decreasing choices in many areas of life. During a hospital stay it is important to strive to maintain a sense of self and if a person's identity is threatened at this time a person may feel increasingly vulnerable. A person may feel threatened when deep-rooted needs for autonomy, for continuity in self-definition, for distinctiveness and for self esteem are prevented from being fulfilled (Breakwell 1986). The lack of control over changes being imposed on the person by the disability constitutes another threat to identity which can affect self esteem and disrupt a person's continuing sense of self-definition. During this time a person's ability to cope will be of paramount importance, but also of overwhelming influence will be the way a person is treated by staff and others during their stay in hospital. Staff may be ready to jump to conclusions about the patient based on their own attitudinal and value system. Indeed, Kerr (1970) suggests that before problems such as dependence and over-demandingness are attributed to a personal defect on the patient's part, a number of important questions need to be asked: does the patient have reasons to believe that they can succeed in the task required, is the patient assured of social contact and the right kind of attention if they develop self-care skills or is the patient angry or afraid? These questions set the patient's personal meanings into the social context of the hospital and invite a look at the relationships therein. In order to explore some the reasons staff may have preconceived ideas about the patients for whom they care, an examination of the social context is vital to look at the cultural origins as to how society has dealt with the issue of disability.

1.8 The Social Context

Our perceptions of individuals with a disability, or acquired disability such as a stroke, have been heavily influenced in recent years by the development of hospital based medicine and rehabilitation services which have grown within the medical model of service provision. This model is based on an assumption that there is something intrinsically wrong with disabled people which results in their experience of limited opportunities (Finkelstein 1980). This individual deficiency can be viewed as a personal tragedy which means that disabled people need to be looked after and receive care. Charities have also been established whose whole ethos is to help these 'unfortunates' and their funding raising efforts have often adopted an approach based on the tragedy model.

The medical model also puts impairment as the primary focus of concern and treatment is based on the assumption that the quality of life of disabled people can be best improved by resolving or limiting the impairment through treatments aimed at curing the individual. Disabled people undergo medical treatment and rehabilitation to try and be as 'normal' as possible. However, when interventions do not 'cure', the individual disabled person is likely to be perceived as having a permanent medical problem or illness. Even though the medical model has inadequacies it is difficult to challenge. Firstly, for many individuals, who have lost a degree of functioning, initially desire to regain as much of their potential as possible; even though 14.2% of the adult population who experience an impairment through accident or illness will not be cured (Martin 1988). The second problem results from the considerable level of expertise by practitioners working in this field who have been given considerable power over disabled people's treatment and their lives, and any challenge to the medical model would challenge their status. It has been shown that even when there is little evidence of probable benefit to a patient a medical means of treatment is still chosen. Duckworth (1997) noted that individuals on a rehabilitation unit with a spinal injury are often instructed to use a standing frame at least twice a week and they are told this will help with bladder functioning and reduces spasms. However, research has shown that this is not the case and yet this treatment is still carried out which is not only very painful but also costly in terms of staff time.

The inadequacy of the medical model has led to the development of the social model of disability which shifts the emphasis away from the individual and whose proponents have fuelled a whole movement which has some degree of political influence today. This movement has grown out of the lived experience of injustice and growing collective identity of disabled people which looks in terms at the socially imposed restriction in the physical and social environment (Oliver 1987). This can be illustrated by an amusing article by Finkelstein (1981) who notes that if the physical and social world was adapted for wheelchair users their disabilities would disappear and able-bodied people would become disabled! Disability as a category can only be understood within a framework that suggests that it is both culturally produced and socially structured (Oliver 1990). The core values of society which involve our superstitious, religious or philosophical values also have a role to play.

The WHO definition of disability with the focus on ‘impairment’, ‘disability’ and ‘handicap’ is also thought to have developed because of the focus on the impairments of individuals as the ultimate cause of disability (Finkelstein 1980). It is argued that these definitions are based upon able bodied assumptions of disability and they do not accord with the personal realities for a disabled person (Oliver 1983). These assumptions are thought to arise from a personal tragedy theory rather than as one of social oppression. This tragedy theory has developed historically with key stereotypes of disability within a history of misrepresentation. Stereotypes such as Long John Silver and the Hunch back of Notre Dame have done much to shape our view of disability. If disabled people are seen as victims of some tragic happening as is represented in all forms of the media (Hevey 1997) then social policies will be structured to attempt to compensate these victims for the tragedy. However, if disability is defined as social oppression then social policies will be geared towards alleviating oppression rather than compensation (Oliver 1997). The definition proposed by the Union of the Physically Impaired Against Segregation and the International Disability Association, Disabled People's International is that 'Impairment' is the lack of part of or all of a limb, or having a defective limb, organ or mechanism of the body and 'Disability' is the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers. The growth of new organisations of disabled people during the past two decades have been compared to the development of the black and feminist movement for civil rights (Morris 1991). The common feature of race, gender and disability is that of discrimination by society which has a negative view towards certain groups. The implication of this discrimination is that disabled people come out very badly on every indicator of participation in mainstream life: employment statistics, income levels, suitable housing and access to public transport, buildings, information and leisure facilities. To understand these implications further we need to explore attitudes in more detail because our attitudes are often derived from a social context and can have a significant influence on our behaviour in general which itself has important implications for the way in which we work with individuals with an acquired disability on a rehabilitation ward.

1.8.1 Attitude, discrimination and prejudice

The social context which will have at its core issues of discrimination and negativity from the population as a whole has certain implications for the micro environment that operates within and between individuals in a rehabilitation ward. It could be argued that in this context the role of the professional and the team in rehabilitation is of prime importance because the relationship with rehabilitation staff are the first significant post injury contact and this could have a far reaching positive effect or impede rehabilitation. With this in mind staff attitudes in rehabilitation are crucial in determining an individual response to rehabilitation than any other force (Tucker 1980, McDaniel 1975). Although the research is conflicting, French (1994) concludes that there is room for improvement in the attitudes of health professionals towards disabled people.

In this context it would be useful to examine the definition of attitude. An attitude can be defined as: 'enduring mental representations of various features of the social or physical world. They are acquired through experience and exert a directive influence on subsequent behaviour' (Baron and Byrne 1991). Most definitions of attitude comprise three components: cognitive, affective and behavioural. The cognitive component refers to our beliefs about the object or person to whom the attitude is directed. We may believe that a person who has a stroke is damaged. The affective component refers to our evaluation of the object or person to whom the attitude is directed. So we may believe that a stroke has made this person inferior. The more important or central our beliefs and values the more difficult they are for us or others to change. That is because they underpin other attitudes and may influence the way we behave, although the degree that this occurs may be limited (Fishbein and Ajken 1975).

Negative attitudes towards disability have the potential to develop into a prejudice. Prejudice can be defined as 'a negative attitude towards a particular group of persons based on negative traits assumed to be uniformly displayed by all members of that group' (Reber 1985). Prejudices like attitudes have cognitive, affective and behavioural components (French 1996). The cognitive component is a stereotype which can be defined as an exaggerated belief and oversimplified or uncritical judgement about a group of people. The affective component involves a feeling and the behavioural component may manifest itself as discrimination culminating in aggression or preferential treatment. Professionals may learn to rely on culturally acceptable stereotypes of disabled people as a way of handling their clients and surviving the organisation where they work (Holmes and Karst 1990). Stereotypes may strengthen negative attitudes towards disabled people who may be expected to behave as passive recipients of care for example, yet when they comply their behaviour may validate and reinforce prevailing attitudes that they are inferior or incapable of self-determination (French 1996). A particular set of behaviours often referred to as the disabled role, may be expected of disabled people so strongly that those who do not conform are viewed in negative terms (French 1994). The prejudices that are held against disabled people may become part of their own self-identity and view of the world leading to a self-fulfilling prophecy. As a consequence disabled people may experience a phenomenon called 'learned helplessness' (Seligman 1975) which could render a person passive, dependent and unable to made decisions for themselves. These processes are rarely at a conscious level so health professionals do not necessarily guard against them or even think about them. This situation is exacerbated by the large, impersonal organisations where most health professionals' work and the powerful dynamics of the differences in terms of power between staff and patients.

1.8.2 Ageism

In addition, ageism (Butler 1980) may represent a stereotypical set of beliefs about and towards older people which again could impact on an individual experience during their stay in hospital. Although the Social model of disability deals with physical disability which is an important aspect of a stroke it does not consider the effects of age and as incidence rates show that stroke is largely a disease of older adults this is an important consideration. There are some debilitating consequences of growing older in society today and the concept of ageism has been used to try and address this issue. One of the first definitions of ageism was proposed by Butler (1969) who described it as "the systematic stereotyping of and discrimination against people because they are old, just as racism and sexism accomplish this with skin, colour and gender". A more recent working definition has been proffered by Bytheway and Johnson (1990) who state that ageism is a set of beliefs originating in the biological variation between people and relating to the ageing process. In consequence they state that it follows that "ageism generates and reinforces a fear and denigration of the ageing process and stereotyping presumptions regarding competence and the need for protection". They also note that ageism legitimates the use of chronological age to mark out classes of people who are systematically denied resources and opportunities that others enjoy and who suffer the consequences of such denigration, ranging from well meaning patronage to unambiguous vilification.

The social dependency of older adults is another avenue through which ageism is perpetuated and Townsend (1981) argues that the concepts of retirement, pensionable status, institutional, residential and other passive forms of community care serve to reinforce this social dependency. This form of community care reinforces dependency by creating marginalisation and a sense of powerlessness (Biggs 1994) and these factors may be some of the principle forces which affects older people's lives today.

The consequences of the ageism can be seen in many aspects of our society. For example, age discrimination in terms of opportunities for employment are prevalent and is it not unusual to be newspaper articles with headlines such as 'job hopes fade for the over 55' (Daily Telegraph Newspaper 1994) which implies that over a certain age a person is not such a valuable commodity in the job market. This is based on chronological age rather than a person's ability to work Discrimination can also be seen in the provision of health services and elderly people are regularly refused life saving treatment because of their age not medical condition. For example, Dudley and Burns (1992) found in a study of 175 coronary care units that 20% operated an age related admissions policy and 40% had age related policies on using thrombolytic drugs which were found to be most beneficial for the over 70's. It may be argued that this policy is based upon that fact that older people have lower survival rate and therefore poorer outcomes on this drug. However, if this drug is efficacious for older adults and improves their quality of life, even if that period of time is limited, then it is still ageist to deny older people the right to this drug.

1.8.3 Physical disability and age

Older persons with a disability are probably handicapped even more than a younger person because of society's attitude toward disabled persons and therefore may suffer a double jeopardy (Rubenfield 1986). It is interesting that this has been coined 'double oppression' (Oliver 1990) in reference to black individuals who are disabled. However, this term has recently been disputed by Stuart (1997) who rejects the idea that black disabled people experience a kind of double oppression. He argues that for these people racism involves a process of simultaneous oppression in their day-to-day experience, which may be a way of viewing the situation for older people who also have a physical disability. Given that discrimination is thought to be so rife in our society it is vital that the attitudes of health professionals be examined for the fundamental reason that they could negatively effect the self-image and recovery of disabled older people (Paris 1993). With this in mind, it is important to consider if health professionals are merely reflecting the views of society.

1.8.4 Health professionals' attitudes to individuals with a disability

Research evidence regarding whether the attitudes of health professional are more or less positive than those of the general public tend to conflict (Vargo and Semple 1988). In an examination of physiotherapy, Vargo and Semple (1988) tested final year physiotherapy students and found more positive attitudes towards disabled people when the students responded 'professionally' rather than 'personally'. Attitudes of student physiotherapists towards disabled people were similar to those of the general public and did not become substantially more positive after a theoretical training course (Gething and Westbrook 1983) but their attitudes were more positive than students of other occupations. A number of disabled people were asked their view of physiotherapists' attitudes and all participants stated that although good personal relationships developed with some physiotherapists insensitive and condescending attitudes were a common experience (Johnson 1993).

For the Occupational Therapy profession, Lyons (1991) found that the attitudes of occupational therapy students did not vary with the years of undergraduate education completed. This finding was confirmed by Lyons and Hayes (1993) some years later, who also noted that those students who had had contact with persons with disabilities beyond the context of a caregiver-care receiver relationship had more positive attitudes. So it appears that the power imbalance that is experienced may have something to do with the maintenance of attitudes despite repeated exposure.

With respect to nursing, Brillhart et al. (1990) found that first year nursing students had more positive attitudes towards disabled people than graduating nurses. In terms of the attitudes of doctors some studies show that they improve during training (Mitchell et al 1984) and fourth year medical students have been found to have more positive attitudes than first year medical students (Paris 1993). Whereas other studies have found no difference (Duckworth 1988). There is some research to suggest that a medical education tended to increase cynicism (Rezler 1974) and reduce empathy (Diseker and Michielutte 1981).

In summary, the weight of evidence suggests that attitudes of health professionals are not very different from those of the general public. Allen and Birse (1991) also confirmed that health care professionals share the values and expectations of their society and show the same reactions that unstigmatised individuals have towards those with differences. Perhaps it is that professionals attitudes remain the same because they reflect deeply rooted beliefs that are not changed with exposure. It may also mean that attitudes don't change because there is always a power balance difference between the 'healthy' professional and the 'disabled' patient. This imbalance is never redressed by exposure of the health professionals to individuals who, despite being disabled, have an equal status, such as an important job or qualification. Attitudes may also remain unchanged for health professionals because they have not received any training on this subject. The role of education is thought to have a significant effect on attitudes because when a learning programme was introduced to a group of nursing students designed to promote a positive attitude there was some improvement (Rosswurn 1980). Some of the inconsistencies in the research may also be due to the differing nature of professional and personal attitudes and the attitudes of health professionals varied according to the social context, in that, they were more favourably disposed to working with disabled people than marrying them (Gordon et al 1990). This confirms the finding that people's beliefs about the way disabled people should be treated by society and their own personal reactions to disabled people were often in conflict (Leonard and Crawford 1989).

The influence of attitude has probably received the most attention in the literature but generally speaking, attitudes and behaviour tend to be poorly correlated and it has been found that only approximately 10% of the variance of our behaviour can be explained by attitudes. Many other factors influence our behaviour as Gross (1987) states 'it is generally agreed that attitudes are only one determinant of behaviour; they represent predisposition's to behave but how we actually act in a particular situation will depend on the immediate consequences of our behaviour, how we think others will evaluate our actions, and habitual ways of behaving in those kinds of situations'. Although attitudes predict behaviour to a limited extent, situational factors often have a stronger influence. In addition, individual differences are paramount, in that, one person may be more inclined to keep consistency between their attitudes and behaviour than others who may change their attitudes depending on the social context or group pressure. Because of the inconsistency of response, research in this area has proved problematical in that general attitudes do not always predict specific behaviour. Fishbein and Ajken (1975) agree that general attitudes are poor predictors of specific behaviour and that to obtain a positive correlation both the attitude and the behaviour must be specific. Given the challenges of working in the arena of attitudes, it is important to focus on the fact that attitudes do predispose individuals to behave in a certain ways and that this predisposition may have the potential to set up a whole culture of behaviour amongst professional groups, which has arisen from similar attitudes.

Although, the degree to which attitudes will predict behaviour is variable and will depend on other influences such as habits, social norms and group pressure (Gross 1987), what actually occurs at the level of everyday interactions on a rehabilitation ward is obviously of prime importance. It is therefore essential to examine the potential barriers that can prevent the formation of effective therapeutic alliances which are likely to have an detrimental effect not only on the process but also the outcome of rehabilitation for the individual. This is confirmed by Bozarth (1981) who emphasised the importance of attitudes by indicating that the success or failure of a client rehabilitation programme may be influenced by the counsellor attitudes towards the client. Garske and Thomas (1990) state that it is of the utmost importance that those working in rehabilitation exhibit positive attitudes because they are significant in shaping the lifestyle opportunities generated for the person with a disability and the role they are encouraged to adopt in society (Benham 1988).

Some research has indicated that nurses attitudes may have an effect on the quality of nurse-patient communication. Nurses with a more favourable attitudes towards elderly people thought it more important to have social interaction with patients than to provide hygienic care (Armstrong-Ester et al. 1989). On the other hand, Salmon (1993) could not demonstrate a relationship between nurses' attitudes towards the elderly and their communicative behaviour. Despite the variability in the degree to which a nurses attitude will affect their behaviour, much work has focussed on how to achieve attitude change amongst professionals.

The hope that attitude change will lead to an overall improvement in rehabilitation services has been reiterated by Rousch (1986) who asserts that one of the major challenges of rehabilitation in the 1980's is not the development of new technology and miracle drugs but to overcome attitudinal barriers in interaction and relationships through understanding and acceptance.

Before examining attitude change in relation to rehabilitation it is important to consider the function of attitudes. Firstly, attitudes serve many important functions relating to our psychological well-being. Atkinson et al (1993) note that they have an adaptive function, in that, we may develop similar attitudes to those people we like, or to those with whom we work, in order to maintain the pleasure of their company and avoid conflict. They help us to achieve and maintain social adjustment and avoid isolation. A knowledge function helps us to structure the world by making it simpler and in this way we may form stereotypes of groups to simplify our understanding and responses to them. The function of self expression is also important which allows us to give expression to our underlying beliefs and values. There is also an ego-defensive function whereby we deal with threats to our self esteem by denying or projecting information. Because attitudes serve so many functions they can become very resistant to change and this may partly explain why information will not always necessarily result in attitude change. In addition, it may explain some reasons why a climate on a ward could be the culturally accepted way of staff behaving towards others.

1.8.5 Changing attitudes of health professionals

The two main approaches used to change attitudes of professionals working with disabled people includes information and contact.

However, neither information nor contact alone are thought to be sufficient to alter attitudes towards disabled people and some research has found a combination of both is required (Anthony 1984). Disability Awareness Training has grown in popularity in recent years, although some of the methods frequently used whereby participants simulate physical and sensory disabilities have been heavily criticised. Simulation exercises have been described as insulting to disabled people because they trivialise disability (Finstelstein 1991). There is also growing research which indicates that there is little evidence that simulation exercises have a positive effect on the attitudes of those who undertake them (Semple et al 1980). However despite this evidence, simulation exercises are increasingly being used (Pockney 1989).

In response to the criticisms of other methods aimed at changing attitudes a change in emphasis was advocated by disabled people towards creating a new understanding of disability by changing practices rather than improving general attitudes (Swain and Lawrence 1994). Disability Equality Training (DET) was developed to gain equal opportunities and social justice. DET is a short training programme of one or two days which concentrates on changing the meaning of disability from individual tragedy to social oppression. However, it is difficult to see how this could not but have a positive effect on the beliefs and attitudes of participants. DET is designed to spread acceptance of the social model of disability and demonstrate to different organisations their role in the model by showing how common organisations policies and practices may discriminate against disabled people. (Duckworth 1997). It is recommended that such there should be substantial input from disabled people throughout the education of health professionals which would be best achieved by comprehensive disability equality training conducted by qualified disabled trainers (Duckworth 1988, Lyons and Hayes 1993). The criticism of much of the previous work on attitudes which tries to examine attitudes by way of formal assessment and courses outside of the context of an individual's working environment suggests a way forward in rehabilitation research. Rather than taking staff out and examining their attitudes and attempting some change there is a need to know what is taking place on a rehabilitation ward on a day to day basis and what are the nature of these interactions between staff and patients involved in the rehabilitation process. Not only do researchers need the answers to this type of research but so do the professionals involved because this may help to shape their view and practice.

Contact with disabled people is also thought to be an important ingredient in bringing about positive attitude change (McConkey and McCormack 1983, Berrol 1984, Sampson 1991, Lyons and Hayes 1993). Simple contact on a professional basis does not appear to be enough to bring about positive attitude change because this tends to focus on what the disabled person cannot do (Gething and Westbrook 1983). One factor that consistently seems to promote positive attitudes towards disabled people is equal status contact (Anthony 1977, Yuker and Block 1979, McConkey and McCormack 1983). Many writers also advocate the training and employment of disabled health professionals as a means of changing attitudes within the professions (Turner 1984, Chinnery 1991).

Despite the many techniques that are presently being used to influence the behaviour of professionals working in the field of disability, many believe that there has been an over emphasis on the nature of attitudes in research to date (Potter and Wetherell 1987). They argue that this stems from a belief that many attempts to recover the person's underlying attitudes is often a fruitless task. Their work has tended to focus on discourse itself as a pathway to entities or phenomena lying beyond the text. Language itself is constitutive rather than simply descriptive. The concept of discourse analysis is composed of two main dimensions: textual and contextual. The former is concerned with such micro elements of discourse as the use of grammar, metaphor, syntax, sound forms etc. The latter examines the production and reception processes of discourse with particular attention to the reproduction of ideology power and hegemony in such processes and the links between discourse structures and social interactions and situations. It has been noted that discourse analysis represents an under-utilised methodology for understanding the ideologies of health and illness (Lupton 1992). She goes on to state that because discourse analysis is not simply concerned with the manifest or obvious context of text and talk it also seeks to display the reproduction of ideology and the more subtle forms of control, persuasion and manipulation in the meanings inherent in discourse. It is for this reason that it provides a valuable way of understanding the underlying assumptions inherent in health professionals communication with their patients. This qualitative methodology provides an interesting way forward to examine the nature of communications between staff and professionals in a health setting.

A large proportion of the work looking at attitudes has often focussed almost exclusively on the use of questionnaires to evaluate attitude change without trying to examine what the effect of attitudes may have on communication or interaction between staff and patients. In addition, the crucial assumption of attitude researchers is that there is something enduring within people which the scale is measuring namely the attitude

(Edwards and Potter 1992). This has led to work on the nature of staff-patient communication that is worthy of mention.

1.8.6 Staff and patient communication

Communication between staff and patient can be either verbal or non verbal: verbal communication is spoken while non verbal communications comprises sending forms of messages such as facial expression and gesturing. The majority of research has tended to concentrate on verbal communication in the nursing profession. In an extensive study of the quality and quantity of nurses' communication with surgical patients, Clarke (1983) found that conversations were described as 'friendly', but also 'stereotyped', 'superficial' and short in duration. There is a growing body of literature that suggests that the quality of interpersonal relationships in health care is highly valued by the patient; often the 'human' characteristics of doctors are felt to be more important than their technical skills. This was illustrated by Koos (1955) in a sample of 1000 patients who found that 64% criticised their doctors for lack of warmth with too much emphasis on such technological aspects of care such as tests diagnosis and drugs. This lack of warmth and friendliness on the doctor's part adversely affected communication (Korsch et al. 1968). However, despite the value for the patient the main conclusion of many studies suggests that the interaction between nurses and patient is low (Armstrong-Ester and Browne 1986, Armstrong-Ester et al. 1989, 1994, Allen and Turner 1991) and communicating with patients has been described as a difficult and potentially stressful aspect of nursing. However, newly qualified nurses rated their competence of talking with patients quite highly, although not as highly as giving physical care

(Corner and Wilson-Barnett 1992). Being too busy and not having enough time to talk with patients is frequently offered as a reason for the low quality and quantity of nurse-patient conversation. However, research indicates that nurses do not use quiet, less busy periods to talk with patients. In a study of nurses which were audio-recorded as they went about their normal nursing duties the amount of time the nurse spent in direct one-to-one contact with patients was low, although over 50% of these sessions took place when the nurses described the ward as 'very quiet'. Recent research emphasises the difficulties and importance of communication in particular the need to make more time for patients (Audit Commission 1992). Most nurse-patient conversation takes place during the provision of physical care and therefore the nurses' objective or intention during interaction with patients is mainly concerned with completing the nursing tasks being undertaken (Fielding 1982). Other factors such as fear of death, anxiety about upsetting the patient or not being able to cope, as well as a lack of communication skills are also reasons why the nurse-patient conversations may be so limited (Wilkinson 1991).

Some research has also found that a large percentage (84%) of nurse-patient communication was initiated by the nurse rather than the patients, which suggests that the nurse had more control and authority over the conversation than the patient (Clarke 1983). Lanceley (1995) recently demonstrated how nurses use controlling language during interactions with elderly patients by employing particular words such as 'must' and 'we'. With regard to this issue of power in health care relationships, Barofsky (1978) has argued that the relationship between the patient and the professional almost always starts as unequal, with differences between them which make one more in control than the other. If this relationship remains unequal it is because the patient has little or no influence over the professionals behaviour, and the distribution of power between them is a barrier to the initiation and maintenance of self care behaviour (Horn 1997). Professionals can use a variety of power bases to influence patients' behaviour: expert, legitimate, referent, coercive and reward (French and Raven 1986). If the professional is perceived as an expert patients are more likely to accept his advice. If patients adopt the sick role they may decide the professional has a legitimate role to prescribe a particular path toward a goal. Therefore, the knowledge, beliefs, attitudes and expectations of the patient are still operating on the encounter. Coleman (1985) has identified components of professionals behaviour that have an impact on patient behaviour: among them are compassion, communication and an attitude of concern, with hope and an interest in the patients' future wellbeing. Language has been found to be a way of exerting power over patients (Hewison 1995) this is considered as normal and is accepted by patients and staff. However, Hewison's study concluded that the existing power relationship constrains open communication.

Much of this research has concentrated on what the nurses are saying with scant attention to the contribution of patients (Jarrett and Payne 1995). It may be that patients may also have views about what they feel is appropriate to talk about with nurses which could explain why psychological issues are dealt with on a very superficial level particularly given that nurses are strongly associated with physical rather than psychological care giving (Von Essen and Sjoden 1991). Using conversational analysis Hunt and Meerabeau (1993) noted how ordinary and social much of the conversation was, despite the potentially emotionally charged situation of terminal care. This led them to the conclusion that patients may prefer and help to keep conversations ‘ordinary’.

To examine the way that staff talk to patients in the field of dementia, Kitwood (1990) devised a simple form of critical incident technique, essentially making brief notes on episodes of conversation as soon as possible after they had been observed and then classifying them. For example, he noticed that ‘infantilisation’ frequently occurred whereby a person was spoken to in a very patronising way, or a person would be spoken about in his or presence. He believed that these interactions were frequently observed because of a ‘malignant social psychology’ prevalent in health care. The term malignant did not imply evil intent on the part of caregivers but was steeped in cultural inheritance. So that individuals with dementia were devalued and a ‘them’ and ‘us’ approach to care was adopted. This technique is one approach in trying to examine interactions at the level of the ward environment and to try and use the cultural context to explain the nature of interactions. Other work has been carried out with older people outside of the field of dementia to look at the communication between staff and patients and what emerges are some important factors which are connected with the way staff communicate with a person based on age. This is of particular relevance because the likelihood of a stroke increases with age.

1.8.7 Communication with older patients

Some research has suggested that communication with elderly patients has some specific characteristics. Firstly, there may be barriers to communication due to sensory deficits (Greene et al. 1994). Secondly, elderly patients and nurses appear to have different agendas, in that, the patients, who may feel deprived of social contact, want to continue the interaction with social talk, while the nurse wants to hurry up because she has work to do. Thirdly, it has been proposed that the generation gap make effective communication different for elderly people who may have different values and different expectations from the young (LeMay and Redfern 1987). Many of these issues are closely associated with ageism which has been discussed earlier but will all influence communication dynamics in nursing older patients.

The modification of speech has been found to be a notable aspect of communication between nurses and older patients. This observation has been coined as ‘secondary babytalk’ (De Wilde and De Bot 1989), which is defined as a set of accommodations: including simplification and high and variable pitch, usually addressed to children, but also used in talking with the elderly. Coupland et al. (1991) analysed six characteristics of babytalk: length, complexity imperatives, question sentences repetition and substitutions of pronouns (Ashburn and Gordon 1981). The results show that auxiliary nurses used features of babytalk in communication with geriatric patients. The use of babytalk with older adults may be perceived as patronising and is likely to have negative side effects such as a decrease in well being and a decline of physical and psychological functioning (De Wilde and De Bot 1989).

Barnlund (1978) argues that interpersonal communication is a key issue in health care and talks about ‘communicative negligence’: the failure to listen, the failure to comprehend, the failure to respect and collaborate which can have far reaching implications for service delivery. Given that communication is of such importance it is important to determine what affects its quality and quantity.

There are a number of patient characteristics which seem to be related to nurse patient communication and these include mental alertness and physical ability. Nurses tend to interact significantly less with confused patients (Armstrong-Ester et al. 1986) and those who are more physically dependent (Allen and Turner 1991). Nurses caring for older patients also seem to favour patients which are compliant, co-operative and less demanding (Fielding 1982, Gilliard and Brunstone 1984). Those which are socially adept and appreciative get more attention (Robb 1984), whilst those who complain, are unappreciative, lack communication skills or appear to 'know it all' types or are the least popular (Gilliard and Brunston 1984).

Another variable for consideration in terms of the quality of nurse patient communication revolves around ward characteristics. Nurses that are responsible for the ward tend to be task orientated and brief in their interaction with patients (Thomas1994) and she also noted that the practise of primary nursing was seen to have more patient centred communication than nurses on wards with functional or team nursing, regardless of staff grade.

One of the determinants to have received some consideration in the literature refers to the variables of the nurse and include such factors job satisfaction, education and attitude. Job satisfaction is thought to be a positive factor, in that, nurses with high levels of satisfaction were more sensitive to patients' needs than nurses with lower levels (Kramer and Kerkstra 1991). The differences between trained or untrained nurses in relation to communication seems to be inconclusive. Some research has found no difference (Macleod Clark 1985) and others have noted that trained staff used proportionately more of those strategies which promoted dignity self respect, choice and independence (Davies 1992).

1.9 'Quality' in stroke rehabilitation

The nature of staff patient interactions will ultimately affect the quality of rehabilitation services but this has received little attention to date. There has, however, been an increasing emphasis on quality issues in the Health Service which attempts to try and establish good practice rather than carrying on with procedures and methods which are not efficacious.

The various aspects that contribute to the quality of care on a rehabilitation unit can be divided into three main aspects: the structural characteristics of the service, the process of care and the outcome of the care (Donabedian 1980). The latter is the most researched aspect of rehabilitation. The classification of outcome measures is broken into three main categories - patient-oriented outcomes (including impairment outcomes, disability outcomes and handicap outcomes), patient/carer-oriented outcomes and service-oriented outcomes (Sinclair and Dickinson 1998).

1.9.1 Patient Oriented Outcomes

There are a wide range of patient oriented outcomes and these vary according to what is most appropriate for the person at their particular stage of rehabilitation. Disability outcome is most routinely measured by the Barthel index (Mahoney and Barthel 1965) which assesses the level of independence or dependence for 10 activities of daily living with a score range of 0 (dependent) to 20 (independent). It is quick and easy to use and has been carefully researched and aids systematic assessment of disability and when repeated at intervals this index can indicate the progress of rehabilitation. The main disadvantages of the Barthel index are that it can be insensitive to change (patients may improve or deteriorate without a change in score) and that it has a low ‘ceiling’ (patients may have a maximum score but still be restricted by an inability to go out, cook, clean the house etc). There are many other measures to examine disability in terms of mobility and personal care and include The Nottingham Activities of Daily Living (ADL), Rivermead ADL, and the OPCS Disability Scale to name only a few. To assess outcome for handicap many measures have also been devised and includes the Life Satisfaction Index, the Functional Autonomy Measurement and the London Handicap Scale. There are many other measures to assess psychological functioning and one of the most popular is the HADS (Hospital anxiety and depression scale) because it relevant to a hospital population. The are an enormous amount of measures which assess cognitive functioning and their employment will depend on the individual therapists and/or clinical psychologists choice as to which is most appropriate given the presenting difficulties of the individual. These assessments are done on behalf of the individual but in any assessment of quality it is important to ask the patient what their view on the provision of rehabilitation services.

1.9.2 Patient/Carer Oriented Outcomes

Satisfaction questionnaires are the most popular means to assess patients views and have gained popularity recently. These questionnaires are primarily interested in the patient and family perspective. Pound et al. (1994) found a relatively high level of satisfaction with inpatient care, including communication, and the personal social skills of staff. However, a longitudinal survey of patients' and carers' experiences after stroke reported mixed views (Anderson 1992).

1.9.3 Service Orientated Outcomes

The emphasis of service orientated outcomes is to assess the performance of the unit which often involves audit. All audit work involves a systematic cycle in which the results are fed back to change practice. Within an audit cycle a standard is often set after some initial discussion and data are collected to compare results against that standard. The methodology of clinical audit for rehabilitation teams is still being worked out but a number of core elements are emerging, such as the effectiveness with which specific techniques are applied or specific interactions take place, the overall effectiveness of the individual team members' contribution and the effectiveness and efficiency of the team as a whole in meeting its patients needs (McLellan 1997).

However, within this audit there is a requirement to measure the process of care that contributes to outcome and the development of outcome measures. It has been argued that any process measures could be used as proxy measures of outcome (Stojcevic et al. 1996). To examine elements involved in the process of care in greater depth some work has been done which attempts to examine the nature of the ward and its environment, although the majority of work attempts to examine the quality of care for the patients the emphasis has tended to focus on the nursing profession with a geriatric slant rather than on rehabilitation per se. Research has found that there tends to be an emphasis on a task-based work systems on the ward which is designed to 'get the work done' (Norton et al. 1962). They concluded that 'geriatric nursing has long been recognised as being largely routine work of a particularly heavy nature'. This research has pointed to a lack of communication between nurses and patients, along with an almost complete disregard for the social and emotional aspects of patient care. Despite the general acceptance of the philosophy of individualised care, the intervening 30 years have done little to improve this situation (Nolan et al. 1995) and patients within such an environment are often found to be apathetic with low self esteem (Smith 1983). What is perhaps surprising is the suggestion that nurses do not realise this and perceive their patients as being happy with their care (Spence 1985) and even though nursing staff place a great deal of emphasis on communicating with their patients the reality is that many patients continue to spend most of their time inactive (Nolan et al. 1995). It has also been found that while nursing staff recognised the importance of forming relationships and communication with patients neither the structure of a team or functional nursing facilitated this (Thomas 1994). As a result very low levels of staff-patient interaction outside of expected routines of patient care have been found (Armstrong-Ester et al..1994), despite the fact the nurses of all grades ranked talking to patients as 'important', 'rewarding', and an objective for themselves and the unit.

These findings have particular relevance to long stay care environments and Tomlin (1989) describes these ward environments as ones in which nursing care was batch-provided with little evidence of individual care and this has led to a poor quality of life with patient's minds being numbed by routines and lack of stimulation. It may be assumed that these findings only occur for long stay settings. However, a similar finding has been found in a rehabilitation environment, where the routine approach to care was pervasive with the activity being concentrated in the early morning period (Waters 1994). In considering the impact of such care on patients, Miller and Gwynne (1972) utilised the concept of 'warehousing' and proposed that most care for elderly patients was based on 'minimal warehousing' which is likely to lead to depression, humiliation and boredom.

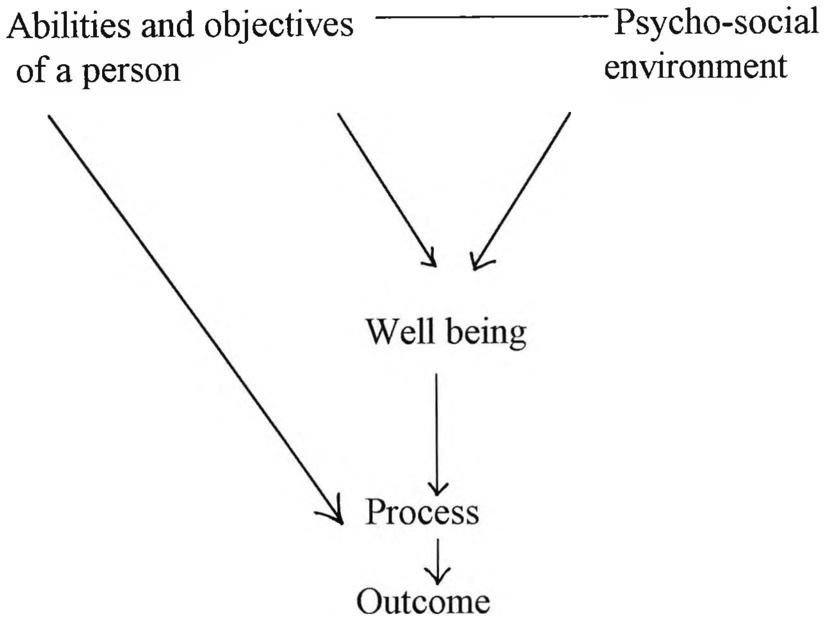
Similar findings have been found within psychiatry where staff spent more time interacting with each other rather than patients, and patients spent most of their time in solitary activities (Sanson-Fisher and Poole 1981). This suggest that the therapeutic potential of psychiatric units investigated in this study was under-utilised. A similar finding by Baltes et al. (1983) who found, in their investigation of nursing homes, that staff spent most of time in terms of social interaction with other members of staff. These studies utilised a very interesting method to evaluate the quality of care in different environments and employed the concept of behavioural mapping procedure as a way of describing the behavioural profile, pattern of interaction and location and patients and staff. It is been a widely used method for evaluating psychiatric treatment environments (Fairbanks et al. 1977, Ittleson et al.1970, Sanson-Fisher et al. 1979).

The work of behavioural mapping to explore quality was explored by Kitwood (1990) in the field of dementia. He examined the nature of the quality of care by dementia care mapping (Kitwood and Bredin 1992) whereby a person's experience was recorded every five minutes and evaluated using a care value. The results of this analysis were summarised and an overall quality of care value assigned. The great strength in this approach which has increased in popularity in England is that it seems to shed light on the actual process of care (Kitwood 1997). Although this work has focused on the field of dementia the applicability of this tool is as yet to be realised. The values which underpin Dementia Care mapping are based on Kitwood's social-psychological theory of personhood in dementia. Stated simply, this theory asserts that although dementia leads to a degeneration of cognitive functioning this does not, of itself, lead individuals to disintegrate from a psychological and emotional point of view. The disintegration occurs largely as a result of the destructive psycho-social environment in which dementia suffers find themselves. The disintegration may be ameliorated by or hastened by the personality or particular coping mechanisms that the sufferer employs. It argues that if the social environment can lead to disintegration of the person's sense and personal worth then the reverse should also be true. In other words, good dementia care, in this context is care which enhances a sense of well being that which enables the sufferer to feel supported, valued and socially confident. This method might be considered a process orientated evaluation of quality and its full value has yet to be explored in rehabilitation.

1.10 Future Directions

This review illustrates a whole range of internal and external factors which are likely to influence an individual who has had a stroke in the rehabilitation process, as shown by the flow chart below:

Figure 2: Flow chart of factors which have an influence on the individual in the process of rehabilitation:



In this chart the abilities and objectives are referring to the individual's personality and motivation and their perceptions of illness. The psycho-social environment refers to the nature of interactions and communication between the patient and the multi-disciplinary team. It is suggested that both of these factors affect the person's well-being which contributes to their sense of personal worth, agency and social confidence and ultimately helps to determine their overall psycho-social adjustment and experience. This flow chart also suggests that this will have some influence on the process of rehabilitation and this has been found to influence outcome (Stojcevic et al. 1996). These issues have received little attention because many of those who work still cling onto the medical model of practice which focuses on the physical aspects of care. The medicalisation of care and control has resulted in pervasive organisational routines particularly in geriatric care (Fairhurst 1981) which are stereotypical and not focussed on the person. Given that many rehabilitation units host a high proportion of older adults very little difference has been found between a rehabilitation ward and one which operates with a routine geriatric style (Baker 1978).

It is therefore vital for research to make the individual and their well being the focus in rehabilitation by attempting to step inside the shoes of an individual who has had a stroke by examining their experiences in terms of the rehabilitation process. This information can be shared with staff who may begin to question their own approach. It is hoped that this kind of focus will increase empathy and identification and lead to mutual participation whereby a professional and patient meet in an adult-adult relationship and thus create a therapeutic environment which facilitates rehabilitation. Szasz and Hollender (1956) observe that in a mutual participation relationship, it is crucial that the participants have approximately equal power, and they are mutually interdependent (need each other) and that they engage in an activity which is satisfying to both of them in some way. The key challenge of the 1990's is how to achieve a relationship between patient and professional which represents an adult-adult exchange. How can the nature of that relationship be captured and communicated to staff? Is there a tool which can be devised for work in stroke rehabilitation which focuses on these issues and raises their importance in the overall quality of care? Can that tool help to change the emphasis on the rehabilitation ward away from a physical preoccupation onto the vital issues of relationships and empathy? Will a tool of this kind help us to gain a greater understanding of the process of rehabilitation and the quality therein? Can a tool answer the call for more information on what actually takes place on a stroke unit that is different from a general ward which has been made by Keith and Cowell (1987) and Tinson (1989)?

A tool widely used in the dementia field may help to fill this gap. This tool has gained increasing popularity over recent years entitled dementia care mapping (Kitwood and Bredin 1992). It is easy to use and has led to positive benefits for both the dementia sufferer and the care staff. A tool of this type may have some benefit in the rehabilitation environment to provide information on the experience of rehabilitation and the value of that experience for the individual which may result in some positive benefits among care staff and the in-patient. This tool would need some revision to be applicable to the rehabilitation setting with the title Stroke Care Mapping. Although there is value itself in evaluating a rehabilitation environment in more depth the most beneficial reason for the use of any tool is its power to affect change. With this in mind it will be necessary to use the results of the revised tool to develop a training package to see if they will result in some changes on the ward. Can this tool be used to evaluate any changes in a meaningful way?

In the development of the tool it is important to see if it will be able to stand alone in capturing the details of what occurs on the ward? Given that a great deal of emphasis in the literature has examined the nature of staff and patient communication will this tool be sensitive enough to capture the nature of this relationship or do we need to consider some way of examining this aspect in further detail? With this in mind what could be used which will help us describe this communication in detail?

Discourse analysis appears to represent a promising way of analysing what is occurring in conversations between staff and patient. It will be useful to see if discourse analysis could be used in conjunction with Stroke Care Mapping or a modified version of discourse analysis be developed which will capture enough detail of the nature of communication between staff and patients?

1.11 Aims of the Present Research

1. To attempt to measure the process of rehabilitation from the individual perspective by using an amended version of Dementia Care Mapping (DCM) tool devised by Tom Kitwood and Kathleen Bredin (1992) applied to the area of stroke which will henceforth be referred to as Stroke Care Mapping (SCM).

2. To examine the process of rehabilitation further by employing discourse analysis to investigate the nature of verbal interactions between staff and patients on the ward.

3. To examine the usefulness and applicability of SCM to analyse the experience of stroke rehabilitation for the person.

4. To determine whether discourse analysis can be used as an additional component of SCM.

5. To determine whether SCM can be used to assist staff to look at rehabilitation from the patient's point of view by:

i) Devising a training programme and integral video for staff on the rehabilitation ward to highlight the results of the SCM and to explore the malignant social psychology (Kitwood 1990).

ii) Re-evaluating any changes that have occurred as a result of the staff training.

CHAPTER 2

2.0 Methods

The methods chapter consists of the following sections:

2.1 Hypotheses
2.2 Qualitative methods
2.5 Participant sample and setting
2.6 Procedure

2.1 Hypotheses

2.1.1 Hypothesis 1

DCM can be applied with some alteration to the area of stroke rehabilitation

2.1.2 Hypothesis 2

SCM can be used to examine the quality of care and the experience of the stroke patient whilst in rehabilitation, which will involve including the input provided by therapists.

2.1.3 Hypothesis 3

A training intervention will have a positive effect on SCM results for individual participants.

2.1.4 Hypothesis 4

Discourse analysis will be helpful in examining the process of rehabilitation in terms of interactions with staff and patients.

2.1.5 Hypothesis 5

Discourse analysis will be a useful additional component of SCM

2.2 Qualitative Methods

The methods used in this research are essentially qualitative in nature. Increasingly within the area of Clinical Psychology there are competing ideas about how best to understand the relationship between practice-based knowledge and more formalised procedures associated with the scientist-practitioner. By subscribing to a model of the scientist as one which corrects the clinician's subjective biases by systematic checking and evaluation through precise quantitative research, the practical experience in applied roles which provide the insights about the complexity of human responses and of interaction can be lost (Davison and Lazarus 1994). This bias has been addressed in recent years, and studies using qualitative methods are increasingly being published and funded (Henwood and McQueen 1998). The present research has focussed on qualitative methods which comprises an amended version of Dementia Care Mapping (method 1) and Discourse Analysis (method 2).

2.2.1 Method 1

2.2.1.1 Details of Dementia Care Mapping

An adapted version of a Dementia Care Mapping (DCM) method devised by two members of the Bradford Dementia Research Group, Tom Kitwood and Kathleen Bredin (Kitwood and Bredin 1994) was used. This tool was designed to make a more detailed and objective appraisal of the care given to dementia sufferers by trying to record care received as perceived by the dementia sufferer. The tool was developed from detailed ethnological observations of dementia sufferers in a variety of settings.

2.2.1.2 Guidelines for Recording Data

The Dementia Care Mapping approach has evolved a whole method of administration which is presented in a manual. A summary of the basic techniques used to derive behaviour category codes, and their use along with the principles behind care values and personal detractions, are presented under the following headings.

2.2.1.3 Behaviour Category Codes

The method involves recording observations of behaviours carried out by the individual with dementia. The behaviour is denoted by letters called Behaviour Category Codes (BCCs), for example, code D refers to expressing distress, and code E refers to being involved in an expressive or creative activity (for a full list see Table 1 on page 73). The mapper follows between five and seven dementia sufferers at various times in a 'normal' day. In each 5 minute interval, one of 22 BCC's that best describes the behaviour is chosen.

Table 2: Behaviour Category Codes

Code	memory cue	general description of category
A	Articulation	Interacting with others verbally or otherwise
B	Borderline	Being socially involved, but passively
C	Cool	Being socially involved but withdrawn
D	Distress	Expressing distress
E	Expression	Engaging in an expressive or creative activity
F	Food	Eating and drinking
G	Games	Participating in a game
H	Handicraft	Participating in a craft activity
I	Intellectual	Using intellectual abilities
J	Joints	Participating in exercise or physical sports
K	Kum and go	Walking, standing, moving in a wheelchair
L	Labour	Performing work or pseudowork
M	Media	Engaging in media
N	Nod, land of	Sleeping , dozing
O	Own care	independently engaging in self care
P	Physical care	Receiving practical, physical or personal care
R	Religion	Participating in a religious activity
S	Sex	Activities related to sexual expression
T	Timulation	Direct engagement of the senses
U	Unresponded to	Communicating without receiving a response
X	X-cretion	Episodes related to excreting
Z	Zero option	Behaviours that fit no existing category

2.2.1.4 Care Values

Each BCC is given an associated care value (CV) which records positive and negative values on the following scale: +5,+3,+1 and -1, -3, -5. Positive values equate with well being, and negative values with ill-being. A table presenting the signs of well/ill being are displayed in Table 2. For example, where a dementia sufferer is demeaned, the care value would be negative. Where the dementia sufferer has been sensitively helped to enjoy their meal, a positive CV would be chosen. There are BCCs that negatively degenerate in CVs, such as sleeping for long periods and being withdrawn or ignored.

Table 3: Signs of well-being and signs of ill-being

Signs of well-being	Signs of ill-being
assertiveness	unattended distress
bodily relaxation	intense or sustained anger
expressing a range of emotions +/-	anxiety
sensitivity emotional needs of others	fear
creative self expression	boredom
demonstrating pleasure	cultural alienation
helpfulness	apathy and withdrawal
affection	despair
self-respect	physical discomfort or pain

2.2.1.5 Rules for determining behaviour

Kitwood and Bredin (1992) introduced the concept of rules for determining which behaviour category code should be mapped and admitted that “there is a degree of arbitrariness about some of these”. Where more than one behaviour is noted in the 5 minute period, guidelines facilitate the person mapping to make a decision as to which code should be recorded. There are rules which determine the mapping of a BCC over a time frame. The rules potentially distort the observation of behaviour because at certain times one BCC will take priority over another. However, Kitwood (1990) introduced these rules to make data collection more manageable even though, at times, this may compromise the behaviour observed.

When the participant engages in different types of behaviour within the same five minute period, the following rules apply:

Rule 1

Dementia Care Mapping distinguishes between Type 1 and Type 11 behaviour category codes. The Type 1 category encompasses active behaviour which have a definite subject such as eating or drinking, whereas, the type 11 category describes a person's state whether that be by communicating or being distressed. In DCM Type 1 behaviour always take priority and there is an order of precedence when assigning behaviour category codes which are:

1.Type 1 categories (**EFGHIJLMOPRSTX**)

2.**K**

3.Type 11 categories (**ABCDU**)

4.**N**

For example, if a participant is looking around the room for the first few minutes of a five minute time frame and then starts to look at a magazine, this would be coded as a **M,** because the Type 1 behaviour takes priority over a Type 11 behaviour which is **B** in this case. In another example, if a person was talking to a patient for a few minutes then began to comb her hair this would be coded as **O** rather than **A.**

Rule 2

When two or more Type 1 behaviours are engaged in during the same five minute period, record the category engaged in most of the time; for example, if a person is putting on their lipstick for the first 4 minutes of a time frame and then starts to drink a cup of tea, the category coding would be **O**.

Rule 3

When two or more Type 1 behaviours are engaged in for roughly the same amount of time, record the category that has the more extreme care value, disregard whether there is a positive or negative care value. If a person is eating lunch in a severe state of ill being then which would be coded as **F-5** but in the latter few minutes starts to read a newspaper which would be coded as **M+1** the category coded would remain **F-5**.

Rule 4

When a participant is engaging in two or more Type 1 behaviours for roughly the same amount of time and which score the same care value number, record the BCC which occurred in the latter part of the five minute period; for example, if a person is knitting for the first few minutes and then puts the knitting down and starts to play dominoes, the category coded would be **G** and not **H**

Rule 5

When a participant is engaging in two or more Type 11 behaviours within a single time frame, use the order of precedence DAUBC regardless of length of time or relative care values; for example, if a person is talking and then begins to look around passively for the next few minutes the category coded would be **A** and not **B**.

Personal Detraction Coding

Notes are also made of the Personal Detractions during the mapping. Examples of this include: **Objectification**, which involves treating someone as though he/she was an object; **Disempowerment**, which means doing tasks for someone that he/she is capable of doing independently; and **Stigmatisation**, in which the dementia sufferer is treated like an alien or a diseased object who becomes an outcast. Each personal detraction is numbered. See SCM manual (Appendix 2) for a full list of Personal Detractions.

2.2.1.7 Data Collation

Results obtained from the mapping sessions can be used to obtain a summary of information. For example, the care value can be processed to obtain the Individual Care Score (ICS). This shows how an individual participant fared on average during the observation period. To see how a person fares in comparison with others in terms of quality of care DCM provides a table which rates the scores obtained. A score of 3.0 and above indicates an excellent score, a score of 2.2-2.9 is very good, 1.5-2.2 is a good score, from 0.8-1.5 is only fair and the score of 0.7 or below suggests that much improvement is needed. The Individual Profile can also be provided which gives an overview of the types and frequency of behaviour and activities an individual has engaged in during the observation period. If a number of individuals are being mapped at the same time then Group Care Scores and Group Profiles can be obtained.

As this method is quite complex, those who wish to carry out DCM are required to carry out a training which lasts 2 days and finishes with a test to ensure that the trainees are able to map independently.

The detailed feedback that is generated from the evaluation shows how individuals and groups of dementia sufferers have fared during the observation period. It also highlights areas where improvements can be made which can then be re-evaluated at a later date.

2.2.1.8 Stroke Care Mapping

It is thought that this method of analysing a person's experience could be easily and beneficially applied to individuals with a stroke for a number of reasons. Firstly, it emphasises an approach which has been referred to as 'personhood'. Secondly, it is relevant to a vulnerable group of individuals. Thirdly, a significant proportion of individuals who have suffered a stroke present with cognitive impairment as is always the case with dementia. The degree and level of cognitive difficulty will vary according to the individual but may involve an inability to communicate his/her needs, problem solving difficulties, and memory loss, to name only a few. Like dementia sufferers, an individual who has suffered a stroke may have serious impairment of mental functioning, while still be 'faring well as a person' (Kitwood and Bredin 1994) and this will undoubtedly be affected by the quality of care given.

This study was undertaken to assess the applicability of Dementia Care Mapping to the area of stroke. Dementia Care Mapping attempts to measure the individual patient's experience as the quality of care delivered in terms of interpersonal interactions. It does not rely on traditional patient satisfaction surveys, which are not wholly suitable for individuals with cognitive impairment. Another difficulty with this type of survey is that it is a subjective interpretation of care and because of this Pound et al (1994) supported the need to carry out more objective measures of the person's experience of rehabilitation. However, this is very difficult to achieve and the compromise may be to include a range of approaches. To ask for the patient's view but also where appropriate to try to encourage staff to develop observational skills themselves to look at the process of care that is provided and to develop empathy by examining a person's experience. This approach would therefore seem ideally suitable to rehabilitation because the area of physical disability is one where an individual's sense of self is critically affected by the manner in which support and attitudes from other are experienced.

It is important to point out that individuals undergoing stroke rehabilitation and people who have a dementia and require residential care are 'different' from the majority of other hospital patients. The main difference lies in the fact that these individuals are not 'ill', as is the case for the vast majority of patients in hospital. For individuals with a dementia they are being cared for by professional carers in a care setting. For rehabilitation the individuals are over the 'ill' phase of their stroke and the next stage is to maximise their potential in day to day living.

Dementia Care Mapping can also be criticised for its validity in relation to the application of rules 1,3 and 5. This will mean that on occasions a behaviour is lost because another takes precedence over a five minute period. An attempt to overcome this difficulty is explored further in Chapter 4, whereby an attempt is made to map all behaviours.

To examine the applicability of Dementia Care Mapping to stroke rehabilitation some observations were carried out, which led to the development of the SCM approach.

2.2.1.9 Development of the SCM Manual

A number of hours were spent on the rehabilitation with the Dementia Care Mapping forms and from observations several changes were made to the original manual to make it more applicable to a stroke rehabilitation setting. New categories were included so that behaviour relating to rehabilitation could be recorded. These include Occupational Therapy, Physiotherapy, Speech and Language Therapy, Nursing, Psychology and Medical Care. For those professionals outside of the immediate rehabilitation team Z (zero option, for behaviours that fit no existing category) was used. These categories of behaviour relating to rehabilitation were further broken down into assessment, practice and teaching so that more detail of the activity being undertaken could be recorded. The behaviour category code for **J** (joints) was subsumed into the category which records Physiotherapy sessions. The behaviour category code of **K** was never used to describe therapy activity of walking and standing as undertaken by the new physiotherapy category, but rather the patient moving from one place to another or walking around the ward if they were able. Behaviour category codes were expanded where relevant to show the involvement of other people in these activities, be they professional or visitor (the abbreviations are presented in table 3). In addition, the behaviour category code of **F** (eating and drinking). The category **X** excretion was not included because it was felt this category would not enhance information on the experience of a person's day, and this time was therefore not mapped. For the category of Articulation (**A**) it was felt that it would be useful to know who was talking to the patient and therefore a list of the various individuals who could talk to the patient was devised which is provided below:

Table 4: Abbreviations for the different individuals involved in Behaviour Category Codes

Involvement with a member of staff, during one of the above activities, is as follows using **A** (Articulation) as an example:-

AOT	Interaction with an Occupational Therapist.
AOT(a)	Interaction with an Occupational Therapy assistant.
APHY	Interaction with a Physiotherapist
APHY(a)	Interaction with a Physiotherapy assistant.
ASLT	Interaction with a Speech and Language Therapist.
ANU	Interaction with a Nurse
ANU(a)	Interaction with a Nursing auxiliary.
APSY	Interaction with a Clinical Psychologist
APSY(a)	Interaction with an Psychology assistant
ADOM	Domestic
Av	Interaction with a visitor
Ap	Interaction with a patient

The rules of the DCM were kept the same for SCM 1 and Personal Detractions were used as for the original DCM.

As a result of the changes which arose during the pilot study the following Behaviour Codes were used in SCM 1 and SCM 2 and are presented below in the Table 4 on the next page to show the first amendments of Behaviour Category Codes for Stroke Care Mapping.

Table 5: First Amendments of Behaviour Category Codes

Code	memory cue	general description of category
A	Articulation	Interacting with others verbally or otherwise
B	Borderline	Being socially involved, but passively
C	Cool	Being socially involved but withdrawn
D	Distress	Expressing distress
E	Expression	Engaging in an expressive or creative activity
F **Fd** - dependent feeding,	Food	Eating and drinking
G	Games	Participating in a game
H	Handicraft	participating in a craft activity
I	Intellectual	Using intellectual abilities
K	Kum and go	Walking, standing, moving in a wheelchair
L	Labour	Performing work or pseudowork
M	Media	Engaging in media
N	Nod, land of	Sleeping , dozing
O	Own care	independently engaging in self care
P	Physical care	Receiving practical, physical or personal care
R	Religion	Participating in a religious activity
S	Sex	Activities related to sexual expression
T	Timulation	direct engagement of the senses
U	Unresponded to	Communicating without receiving a response
OT **OTa** - OT assessment **OTp** - OT practice **OTt** - OT teaching	Occupational Therapy	Occupational Therapy sessions
PHY **PHYa** - Physio assessment **PHYp** - Physio practice **PHYt** - Physio teaching	Physiotherapy	Physiotherapy sessions
SLT **SLTa** - SLT assessment **SLTp** - SLT practice **SLTt** - SLT teaching	Speech and Language Therapy	Speech and Language Therapy sessions.
NU **NUa** - Nursing assessment **NUp** - Nursing practice **NUt** - Nursing teaching	Nursing Care	Episodes of nursing care
PSY **PSYa** - Psychological assess. **PSYp** - Psychological practice **PSYt** - Psychological teaching	Psychology	Psychology sessions
MC **MCa** - Medical assessment	Medical Care	Medical care by a Doctor.

2.2.2.0 Example of SCM

To illustrate how this tool worked in practise a sample of mapping undertaken with P4 during SCM 1 is presented below:

<table>
<tr><td colspan="3">Participants name:
P4</td><td colspan="3">Date:
7.11.97</td><td colspan="4">Time Period:
0905-1000</td><td colspan="4">Observer:
HG</td></tr>
<tr><td colspan="14">Place:
Samares Rehabilitation Ward</td></tr>
<tr><td>Time</td><td>0905</td><td>0910</td><td>0915</td><td>0920</td><td>0925</td><td>0930</td><td>0935</td><td>0940</td><td>0945</td><td>0950</td><td>0955</td><td>1000</td><td>1005</td></tr>
<tr><td>BCC</td><td>OT
p</td><td>OT
p</td><td>OT
p</td><td>OT
p</td><td>OT
p</td><td>OT
p</td><td>OT
p</td><td>OT
p</td><td>F</td><td>F</td><td>F</td><td>B</td><td></td></tr>
<tr><td>CV</td><td>---</td><td>---</td><td>---</td><td>---</td><td>---</td><td>---</td><td>---</td><td>---</td><td>+3</td><td>+3</td><td>+3</td><td>+1</td><td></td></tr>
</table>

During this hour it can be seen from the mapping that P4 spent 40 minutes having Occupational Therapy practice. This was not assigned a care value because the activity was occurring behind a curtain. After receiving OT the participant spent 15 minutes having breakfast and this has a mean CV of +3. For the next five minutes P4 is looking around passively.

2.2.2 Method 2

The main method utilised is 'discourse analysis', which has been described as a "functionally orientated approach to naturally occurring analysis of talk and text" (Potter and Mulkay 1985, Potter and Wetherell 1989). This analysis was chosen so that conversational text could be categorised. This approach is not possible with conversational analysis which uses methods which are basically inductive along with a search for recurring patterns. Discourse analysis is composed of two main dimensions; the textual and contextual (Lupton 1992). The textual dimension is principally concerned with micro elements of discourse such as the use of grammar, syntax and the overt meaning of words and sentences in talk although macro elements such as topics and themes are also considered. The contextual dimension examines the production and reception processes of discourse, with particular attention to the reproduction of ideology and the links between discourse structures and social interaction and situations. "The emphasis is not so much upon the message itself but upon the elements and influences in the discourse process as a whole" (Lupton 1992).

2.2.2.1 Transcription Rules for Discourse Analysis

The rules used to transcribe the conversations were derived from Perkins (1997) in her manual. Table 2.5 below is an example of the transcription conventions used for the Discourse Analysis:

Table 6: Transcription conventions used for Discourse Analysis

Symbol	Explanation
[ ]	The point at which the utterances above and below the symbol are produced in overlap
•	The point at which the current turn emerges from overlap
(x syll)	In audible syllables
( )	Uncertain passages of transcript
hhh	Audible out-breath
‘hhh	Audible in-breath
{ }	Non-verbal activity
?	A rising inflection (not necessarily a question)
(.)	Micropause
(0.0)	Pauses or gaps in tenths of seconds
CP	Conversational partner
P	Patient
BC	Background Conversation (in italics)

N	Nurse
OT	Occupational Therapist
SLT	Speech and language Therapist
PT	Physiotherapist
AP	Assistant Psychologist

These symbols were used to analyse the taped conversations of the participants. The contents of the transcripts was separated into various categories depending on the speakers. The main conversation was between the patients and the conversational partner which would either be a professional, or visitor (CP-P and P-CP). The background conversations were also analysed by looking at nurse-patient conversations (N-P and P-N) and nurse to nurse (N-N). There were too few examples of patient to patient interactions to be included in this study.

2.3 Participants Sample and ward setting (participant details are given in Chapter 3)

2.3.1 Location of rehabilitation ward

All participants were taken from Samares ward which is the only rehabilitation ward in Jersey. The ward is an "L" shape 28-bed unit which is divided into "A" and "B" sides. Because of its shape the two sides of the ward are physically quite separate from each other. Each side has different staff who rotate between the two sites on a three monthly cycle. When a person first enters the Samares ward they are immediately placed on the "A" side. As they progress in their rehabilitation and move towards discharge then they are moved to "B" side.

Samares ward does not offer rehabilitation specifically to stroke and its patients include all client groups for whom a rehabilitation approach is suitable; for example patients with other types of brain damage such as a head injury or anoxia, amputation and other neurological diseases. Table 2.6 below provides a rough breakdown of types of admission for 1995 and 1996.

Table 7: Samares Ward Admission by client group

Client Group	1995	%	1996	%
CVA	39	28.9	11	39.3
Head Injury	3	2.2	1	3.6
Other	93	68.9	16	57.1
Total	135	100	28	100

CVA (Cerebral Vascular Assault)

This table shows that approximately 40% of all individuals admitted to the ward in 1996 have had a stroke which represents an increase of over 10% from 1995. The 'Other' category refers to patients for whom it is decided a rehabilitation approach would be suitable and often includes those with reduced mobility.

2.3.2 Multi-disciplinary team on rehabilitation ward

The rehabilitation ward has a multi-disciplinary team consisting of:

28	Nurses (staff nurses and nurses auxiliaries)
1	Physiotherapist
1	Physiotherapy Assistant
1	Occupational Therapist
1	Occupational Therapy Assistant
1	Speech and Language Therapist

In addition, there is also input from a Social Worker, a Clinical Psychologist, a Psychology Assistant, an Ophthalmologist, and two medical Consultants (a Geriatrician and a Neurologist) along with their Registrars.

2.3.3 Procedures of ward

Individuals admitted to the ward generally arrive from Jersey General Hospital following the resolution of the acute phase of a stroke, and are initially received onto "A" side of the ward. Shortly following admission various professionals each make their initial assessments, and then formulate separate goals for the individual. These are usually set within disciplines. Once the person has settled in, an invitation is made to the patient and their relatives to attend a progress meeting to discuss what has been achieved so far and what the next steps in their rehabilitation will involve. This meeting is attended by those professionals who have involvement with the case. During the period of rehabilitation it is possible that another progress meeting will be held if it is deemed necessary. When the individual is nearing the end of their rehabilitation stay a discharge planning meeting will be organised to discuss arrangements for leaving the rehabilitation unit and returning back home or moving to a permanent care setting. During a person's stay they will be discussed amongst all of the team at the weekly ward round which is led by the consultant and serves the purpose of updating the medical team. Each day there is also a meeting at lunchtime between the core disciplines involved in rehabilitation to discuss individuals on the ward. In terms of paperwork in connection with the patient each discipline keeps their own notes.

2.3.4 Selection of Patients

Only those individuals who had suffered a stroke were chosen for the study. In addition, in the selection of individuals it was necessary to attempt to choose those individuals who were likely to remain on the rehabilitation ward for an additional period of two months, the period of time necessary for the mapping and staff training to be completed. Ward staff were consulted about those patients who were likely to remain on the ward and these patients were selected on a random basis.

2.3.5 Consent

2.3.5.1 Patient

Potential participants were sent a letter with an information sheet and a consent form (see appendix 1,2,3). Patients were asked to sign a consent form for the study and assured that non participation would not prejudice their care.

2.3.5.2 Professional

Rehabilitation professionals were also asked by letter for their consent to the above study and the two Consultants on Samares Ward provided their permission to carry out the research.

2.3.5.3 Health and Social Services

Approval from the States of Jersey Health and Social Services Ethics Committee was also obtained.

2.4 Procedure

2.4.1 Duration of Stroke Care Mapping

The mapping took place from 9.00am to 4.00pm with a break of one hour from 1.00pm to 2.00pm at the end of 1997 and beginning of 1998. The mapping took place during these times because an attempt was made to capture the experience of a day. Only one individual was mapped at a time because it was necessary to follow the individual around during the various therapy sessions. Mapping was carried out as unobtrusively as possible. To attempt to control for observer effects on the data before beginning the main observation on each ward, time was spent on the ward both informally and formally observing each subject with the intention that subjects would become used to the researcher's presence. In addition, the mappers always tried to place themselves out of the way of the activities of the ward, whilst still being in a position to observe. It is important to note that a person was not mapped if they were receiving care from behind a curtain, or in the bathroom and toilet.

All patients were mapped for one day on two separate occasions which will hitherto be referred to as SCM 1 and SCM 2. In the intervening period between SCM 1 and SCM 2 a staff training intervention took place on the ward. It is important to note that between both mappings the nursing staff did not rotate.

2.4.2 Duration and context of discourse analysis

It was thought to be important to obtain a variety of different types of interactions from different professionals and different settings during the course of mapping. For some subjects recordings were made in different situations lasting for some 15 minutes. The situations can be divided into 3 separate contexts: the dining room, therapy sessions, and the ward. The dining room also functions as a day room and is adapted for mealtimes which may explain why patients were often brought into the dining areas well before the meal was ready to be served. The therapy sessions took place on the ward and in the separate therapy areas attached to the ward. It was easier to obtain conversational text during therapy sessions, however; it proved more difficult on the ward, where the researcher switched on the tape recorder when conversation involving the patient occurred. For the dining room this was virtually impossible because so little conversation took place.

2.4.3 Details of staff training

Following the completion of the SCM 1 all staff on the rehabilitation unit took part in staff training. Ideally, training of all the staff would take place at the same time to ensure they all received exactly the same training input; however, because of the practical difficulties and limitations of funding it was not possible to release such a large number of staff all at the same time. Therefore, training was organised on a daily basis at a time most convenient for staff. It was decided that training would take place between 2.00-3.00pm each afternoon and that each member of staff would attend one session each week for four weeks. Six was the maximum number of staff at each training session. Training groups were organised so that a range of professionals were represented. The results of the training are presented in 3.21. The structure of the training programme was as follows:

2.4.3.1 Sessions 1 and 2: Feedback and discussion

Aim:

To begin to look more objectively at the experience of care for individuals on the rehabilitation unit.

Objectives:

- To become familiar with the purpose and workings of Stroke Care Mapping
- To receive feedback on the results of the SCM on Samares Ward
- To look for avenues of possible change as a result of feedback

Structure:

- To provide an historical perspective on the development of SCM from DCM
- To examine the reasons why there has always been an overemphasis on physical gains to the exclusion of the importance of psycho-social issues

- To discuss the importance of the psycho-social environment and how it relates to well being
- To show staff the manual produced for SCM and explain mapping of behaviour and the allocation of care values
- To provide the results of each person mapped and provide details on their experience of a rehabilitation day
- To feed back results of the discourse analysis
- To provide a summary of Behaviour Category Codes for those individuals mapped with percentages of amount of time spent in each category and the associated care values.
- To ask for comments on the findings of the SCM
- To divide up into pairs and carry out an exercise which asks staff to imagine they are on a rehabilitation ward and to write down what they would want to ensure happened to them during their period of rehabilitation
- To ask for feedback and ask staff to compare this with the results obtained for the SCM
- To ask staff to put forward recommendations for change on their ward

2.4.3.2 Session 3 : On Personhood:

Aims:

- To create an understanding of the 'malignant social psychology' that can occur in care settings.

Objectives:

- To look at some of the reasons why the development of the 'them' and 'us' approach can occur

- To examine the concept of personhood
- To become familiar with the different types of malignant social psychology that exist
- To be able to recognise various types of personal detractions in everyday interactions

Structure:

- To provide an introduction to the video, entitled 'Personhood' which was produced especially by the researcher involving actors recruited from the Jersey Amateur Dramatic Society for role plays)
- To show the video
- To distribute a list of Personal Detractions as shown in Appendix 1 with an explanation of their use
- To carry out exercises on identifying personal detractions from the role plays on the video and to facilitate subsequent discussion
- To provide a homework task of recognising the personal detractions which occur on the ward
- To involve staff in role plays of patient and carer to illustrate the Personal Detractions that have occurred during the first mapping and to discuss their experience of the role play.
- To provide some reading material on a person's experience of having a stroke entitled 'Rehabilitation following a stroke: a participants perspective' by Robin Cant (Disability and Rehabilitation 1997: Vol 19. No 7, p297-304 and for staff to provide comments at the final session.

2.4.3.3 Session 4: on Attitudes

Aims:

- To create a further understanding of how our attitudes towards older adults and individuals with a physical disability may affect the relationship between carers and clients.

Objectives:

- To recognise stereotypical attitudes
- To explore ageism/discrimination and how it might affect a relationship
- To see how we might change our practice aimed at reducing discriminatory practice

Structure:

- Staff explore their own stereotypical attitudes and define what is a 'stereotype'.
- Staff in pairs to identify their attitudes towards ageing by suggesting words which they think describe old age and then physical disability and discuss the number of positive and negative suggestions.
- Individually to complete a quiz on the myths of growing old
- Brainstorm the effects of ageism on society
- Discussion on how carers can help older people voice their needs and how these can be met in a non ageist way.

CHAPTER 3

3.0 Results

The results chapter first sets out the results for the individual participants who took part in Stroke Care Mapping (3.1- 3.5), then the collated results of the Stroke Care Mapping (3.6 - 3.14) and finally the results of the discourse analysis (3.14 - 3.17).

3.1 Location of Participants on the ward in SCM 1 and SCM 2

Eight individuals took part in the first phase (SCM 1) of stroke care mapping, six from "A" side and two from "B" side. In the second phase (SCM 2) six individuals were remapped of which two remained on "A" side and 4 had moved up to "B" side. Contrary to expectations at the time of selection, the other two SCM 1 participants had been discharged by the time of SCM 2. Table 8 below sets out the position of each subject at SCM 1 and SCM 2.

Table 8: The Location of Patients at SCM 1 and SCM 2

SCM 1	A/B side	SCM 2	A/B side
P1	A	P1	A
P2	A	P2	discharged
P3	A	P3	B
P4	A	P4	B
P5	A	P5	A
P6	A	P6	discharged
P7	B	P7	B
P8	B	P8	B

3.2 Number of Patients and context for discourse analysis

Conversations were taped in different situations lasting for some 15 minutes for the eight participants on the same day as they were being mapped for SCM 1. An attempt was made to try and cover three contexts per person which were divided into the dining room, therapy sessions and the ward. The dining room functions as a day room as well and is adapted for mealtimes. The therapy sessions took place both on the ward and in the separate therapy areas. The recordings from the ward context took place in the morning with the patients sitting by their bed. Conversations between patients and visitors were not included because it was thought that to tape these conversations was too invasive to a person's privacy. Conversations were taped with members of staff, namely Nurses, Occupational Therapists and the Speech and Language Therapist. However, conversations were not taped for the Physiotherapist because on many occasions a student was present and the Physiotherapist felt that the presence of a tape may make her too nervous. Table 9 below provides details of the contexts in which it was possible to obtain a recording for each participant of sufficient audible quality for analysis and lasting more than one minute:

Table 9: Patients taped conversations (*) in various contexts

Participant	dining room	therapy	ward
P1			*
P2			*
P3	*	*	*
P4	*	*	
P5	*		*
P6	*		*
P7	*	*	*
P8	*	*	

3.3 Details of the taped conversations for each participant

For P1 the ward is the only context to be taped and took place at breakfast time with nurses. In the dining room the transcript was inaudible and no therapy took place on the day of mapping.

For P2 the ward is the only context to be taped and this involves an intervention by nurses. In the dining room the tape was again inaudible.

For P3 all three contexts are taped. There is a brief tape during breakfast time on the ward. P3 was also taped during lunchtime in the dining room and during a session with the occupational therapist.

For P4 the sessions taped include a dressing practice with the occupational therapist and during lunchtime. There was no tape for the ward because no conversation occurred for more than one minute with a professional during this time to be recorded. However, there was one conversation with another patient but this was not recorded because the physiotherapist was there with the student.

For P5 there are sessions recorded for lunchtime in the dining room and a conversation on the ward with the domestic. Unfortunately, the session with the Occupational Therapist was inaudible. It is important to note here that the conversation with the domestic is not included in the overall analysis of the interaction on the ward because it is not representative of what tended to occur on a day to day basis on the ward. However, the conversation itself will be discussed at some stage in the results section.
For P6 the contexts that have been taped include the dining room and the ward setting during breakfast. Unfortunately the therapy session was not

taped because P6 was distressed and it was felt that if the session were taped this may increase her level of distress.

For P7 all three contexts have been taped. There is a session with the Speech and Language Therapist and the Occupational Therapist. In addition, the tape on the ward include the move down to the Speech and Language Therapist. There is also a tape of the lunchtime period.

For P8 the contexts of the dining room and a dressing practice with the OT have been taped. Unfortunately the conversation on the ward was inaudible.

All of the discourse analysis was carried out during SCM 1 because it was not anticipated that discourse analysis would be used to compare SCM 1 and SCM 2. One of the difficulties of carrying this out would be to keep the context and the member of staff stable in a naturalistic setting. What is apparent from one map to another is that therapy is not always consistent and on the ward or the dining room it is possible that conversation will not occur.

3.4 Results for individual participants for SCM 1 with extracts from discourse analysis

Results for the participants are presented in the following form:

1. A brief summary of the individual characteristics of the person, in terms of age, date of admission, length of time on the ward and stroke details.

2. A brief written description of their day for SCM 1 and SCM 2 (only for Participant 1).

3. Individual Profile - this provides information on the types and frequency of behaviour and activities an individual has engaged in during the observation period. At the end of this section the Individual Care Score is noted which provides a score to indicate how an individual participant fared on average during the observation period. To find the individual care score all the relevant care values for a participant are added. This number is divided by the number of time frames.

4. Personal detractions noted during the mapping process.

Only the results for Participant 1 are included in the results section, the other participants can be found in Appendix 2 and for these participants a description of the day is not included.

3.5 Results for Participant 1

Table 10: Basic information for P1

Participant:P1
Age: 83
Admission to Rehabilitation Ward: 20.11.97
Length of time on Rehabilitation Ward prior to SCM: 8 days.
Reason for admission: an infarct in the right MCA territory.

3.5.1 Results of SCM 1

SCM 1 was carried out on 28.11.97

3.5.2 Description of the Day

09.00 -10.00:

P1 was sitting by the bed, in a wheelchair, in night-clothes waiting to be dressed. This hour was spent either asleep or looking around at what was happening on the ward in a passive way. When asleep attempts were made to arouse P1, but this proved difficult. Food was put in front of P1 but this was met with no interest. Nurses tried to encourage P1 to eat, and eventually P1 did eat a small amount, very slowly.

10.00 - 11.00:

40 minutes of this hour was spent by P1 sitting passively, watching with a small amount of interest what was happening on the ward. 15 minutes of this hour could not be observed as P1 was being dressed behind a screen.

11.00 - 12.00:

35 minutes of this hour similarly could not be assessed because P1 was continuing to be dressed behind a screen. At 11.35 P1 was taken in a wheelchair to the area outside the dining room (dining room was closed due to a progress meeting taking place). P1 spent the rest of this hour looking around with minimal interest. At times P1's eyes were closed, but it is felt that P1 was not asleep.

12.00 - 13.00:

P1 continued to stay outside the dining room looking around with minimal interest until 12.25 when the ward clerk moved P1 into the dining room. P1 spent the next 15 minutes looking around with minimal interest until lunch was served at 12.45. The next 15 minutes were spent eating slowly and with minimal interest. The nurses regularly went to encourage P1 to eat.

14.00 - 15.00:

P1 spent this hour asleep.

15.00 - 16.00:

P1 spent this hour asleep.

Table 11:Individual Profile of P1 for SCM 1

Main Behaviour Categories	Time	%	Care Value
(N) Sleeping, dozing	2hrs 20mins	42%	1.0
(B) Socially involved, passively	2hrs	39%	1.0
(F) Eating and drinking	30mins	9%	1.0
(K) Walking and moving	10mins	4%	2.0
(A) Articulation	5mins	2%	3.0

Individual Care Score: 1.6

It can be observed that this person spent the larger proportion of the day asleep; indeed the mapping stopped at 15.40 because P1 was well settled in her sleep cycle. Dementia Care Mapping usually follows a rule of coding sleep during the day as a +1 activity for the first one hour and a half in a residential setting. After this time the care value coding becomes a -1. P1 spent a total of one hour 40 minutes asleep at one time in the afternoon which has been coded as +1 because it was felt that at this stage of her rehabilitation this amount of sleep was appropriate. However, it is important to note that she was not checked during this time or stimulated by any other activity. Generally her overall care value reflects a combination of her sheer tiredness with the limited amount of stimulation she received during the day.

3.5.3 Personal detractions

The personal detractions noted for this lady were:
A:5 Infantilisation - "There you are my little beauty"
A:8 Slightly disparaging remark or put down - "Come on, you can do better than that" (bullying tone)
A:8 Slightly disparaging remark or put down -"You won't get better if you don't eat" (bullying tone)
C:23 Mistreating a participant as an object - "Will you just stick in a piece of food as you go past her" (said within earshot)

It was also noted during this mapping session that the radio station, which can be heard throughout the ward, was changed by a member of staff (without consultation of any of the patients on the ward).

3.5.4 Results of Map 2

SCM 2 was carried out on 11.2.98.

3.5.5 Description of day

09.00-10.00:

The first 30 minutes of this hour were spent behind the bed curtain, while P1 was helped to get dressed. The next 10 minutes were spent chatting to the nurses and then breakfast was served. When P1 was served breakfast she spent some 15 minutes sitting in a wheelchair looking around with minimal interest.

10.00 - 11.00:

During the next hour, P1 continued to eat breakfast sporadically. The Physiotherapist spent five minutes chatting to P1 about what they were going to do together and asked if it would be alright if P1 came down early to the therapy area. She then helped P1 to take tablets. A nurse then spent the next 5 minutes chatting to P1. The Physiotherapist then came back and spent a further 5 minutes chatting socially to P1 about a photograph. Following this, the Psychologist wheeled P1 down the Therapy area, where P1 waited to be attended by the Physiotherapist. During this time, P1 looked around with obvious interest at what the other patients were doing.

11.00 - 12.00:

P1 spent 10 minutes reading a magazine, then 35 minutes looking around the therapy area with great interest. The rest of the hour was spent having physiotherapy.

12.00 - 13.00:

Physiotherapy continued for the first five minutes of this hour, followed by a discussion with the Physiotherapist about P1's progress and likely outcome. The Physiotherapist then took P1 back to the dining room. P1 spent the next 25 minutes in conversation with other patients as they waited at the table for lunch to be served. During this time, there was lots of laughter. The last 15 minutes were spent eating lunch and chatting.

14.00 - 15.00:

P1 was asleep in the wheelchair, in the dayroom.

15.00-16.00:

At 15.05 an auxiliary nurse tried to wake up P1 for a cup of tea. The tea was left next to P1. Another attempt to wake up P1 was made at 15.30. P1 woke up at 15.40 and had the cup of tea. The next 10 minutes were spent looking around with minimal interest.

Table 12:Individual Profile of P1 for SCM 2

Main Behaviour Categories	Time	%	Care Value
(N) Sleeping, dozing	1hrs 40mins	31%	1.0
(B) Socially involved, passively	1hr 20mins	25%	2.0
(A) Articulation	1hr	19%	3.5
(F) Eating and drinking	50mins	15%	1.9
(PHYp) Physiotherapy practice	20mins	6%	3.0
(M)Engaging with the media	10mins	3%	3.0
(K) Walking and Moving	10mins	2%	3.0

Individual Care Score: 2.5

3.5.6 Personal detractions

None.

3.5.7 Comparison of SCM 1 and SCM 2

It is interesting to note that the Individual Care Score on SCM 2 has increased by nearly one full point, from 1.6 to 2.5. This moves the care value from being on the borderline fair/good category to the very good category. This is reflected by a diminution in sleeping by almost an hour. In addition, 33% less time was spent in the socially involved, passive category with a higher care score which means this person was displaying more interest in her surroundings. P1 also spent 19% of the recorded time in conversation with others as compared with only 2% on SCM 1. She also spent slightly more time eating and drinking, with more enjoyment than previously. Therapy was also carried out on the second map which had not occurred on the first map. Generally her overall care value on SCM 2 reflects the increased amount of stimulation she received during the day along with an improvement in her physical health. During the SCM 2 it was observed that there was more social interaction between P1 and the staff than previously, with more interest displayed by staff members who took some time to inquire after P1 and her interests.

3.6 Additional Personal Detractions

There were a number of other Personal Detractions which were heard while conducting SCM 1 and although they did not relate to the individual participants who have been mapped it is useful to include them in this session as a further indication of attitudes on the ward.

3.6.1 Mild Detractions

A:4 Speaking about a participant in his/her presence
"I'll get her breakfast, she'll never get it"
"Well, I'll just tell her to wait then"
"I haven't got time to give him a bath"
"They were wondering whether to leave him or just do him on Monday"
"Has she got any"
"I told him to leave it"
"He's got one over there"

A:5 Infantilisation without malice
"Come on boys - up for lunch"

A:7 Slight disempowerment
Interrupting an Occupational Therapy session without apologising

A:8 Slightly disparaging remarks or putdowns
"I don't want you to pull a face I want you to answer me"

3.6.2 Moderate detractions

B:16 - Disruption
A patient's private TV is switched off and the nurse says "lets have that off for a while"

B:18 Cool Invalidation
Staff are discussing an aspect of care of a patient. The patient adds a comment but the remark is ignored.

3.6.3 Severe detractions

C:23 Mistreating participant as an object

Moving a patient who was asleep in a wheelchair, to a new position at the dinner table. A patient is taken from their bedside and put into the dayroom without any comment about where they are going or why.

C:29 Extremely disparaging remarks from staff
“I’m going to ram it down her throat in a minute, she gets me in such a state” (about a patient, within earshot).

3.7 Comparison of SCM 1 and SCM 2 for Personal Detractions

In SCM 1 there were 6 mild detractions, 6 moderate detractions and 8 severe detractions. This makes a total of 20 personal detractions for the participants mapped during map 1. If the other Personal Detractions which were noted during mapping sessions are collated the number of mild detractions becomes 17, moderate detractions becomes 7 and severe detractions becomes 11, which makes a total of 35 during SCM 1. In SCM 2 no personal detractions were recorded for the participants or in the general ward.

3.8 Time analysis of Behaviour Category Codes and Care Values

For SCM 1 and SCM 2 the Behaviour Category Codes and Care Values were analysed on an hour by hour basis.

3.8.1 Results of Summed behaviour codes by hour for Map 1

Table 13 illustrates the results of the hourly breakdown of the behaviour category codes for all subjects are presented:

Table 13: Hourly Breakdown- SCM 1

0900 - 1000		Mean Care Value 1.6
38.3%	eating.	Care Value: 1.9
32.5%	being socially involved, but passively.	Care Value: 1.05
17.4%	having OT (dressing practice; behind curtain therefore no Care Value assigned)	
9.3%	spent asleep.	Care Value 1.0
8.1%	spent interacting verbally or otherwise.	Care Value: 3.0
5.8%	engaging with the media.	Care Value: 1.0
2.3%	walking, standing or wheelchair moving.	Care Value: 1.0
2.3%	receiving practical, personal or physical care.	Care Value: 3.0
1.1%	independently engaging in own care.	Care Value: 1.0

1000 - 1100		Mean Care Value 2.2
28.7%	being socially involved, passively.	Care Value: 1.0.
17.2%	receiving Physiotherapy practice.	Care Value: 3.12
10.3%	engaging with the media.	Care Value: 2.7
10.3%	receiving Speech and Language Therapy.	Care Value: 3.2
9.2%	walking, standing or wheelchair moving.	Care Value: 1.9
5.7%	interacting verbally or otherwise.	Care Value: 3.0
4.6%	independently engaging in own care.	Care Value: 2.5
4.6%	receiving Occupational Therapy practice.	Care Value: 1.0
1.1%	expressing distress.	Care Value: 1.0
1.1%	eating or drinking.	Care Value: 1.0
1.1%	receiving practical, personal or physical care.	Care Value: 3.0
1.1%	receiving a medical assessment by Doctor.	Care Value: 3.0

1100 - 1200		Mean Care Value 2.0
34%	being socially involved but passively.	Care Value: 1.7
16.6%	receiving Physiotherapy practice.	Care Value: 1.1
13.5%	interacting verbally or otherwise.	Care Value: 3.3
11.5%	walking, standing or wheelchair moving.	Care Value: 3.0
8.3%	spent asleep.	Care Value: 1.0
5.2%	engaging with the media.	Care Value: 1.0
3.1%	independently engaging in own care.	Care Value: 3.0
3.1%	receiving Occupational Therapy practice.	Care Value: 1.0
2%	receiving Speech & Language	

	Therapy practice.	Care Value: **3.0**
1.7%	spent receiving practical, physical or personal care.	Care Value: **3.0**
1%	spent eating or drinking.	Care Value: **1.0**

1200 - 1300		**Mean Care Value 1.6**
37%	being socially involved, but passively.	Care Value: **1.3**
33%	spent eating and drinking.	Care Value: **1.7**
20%	interacting verbally or otherwise.	Care Value: **2.9**
6%	walking, standing or wheelchair moving.	Care Value: **1.8**
3%	engaging with the media.	Care Value: **1.0**
1%	spent asleep.	Care Value: **1.0**

1400 - 1500		**Mean Care Value 2.4**
31.4%	interacting verbally or otherwise.	Care Value: **2.9**
18.6%	engaging with the media.	Care Value: **3.2**
16.7%	spent asleep.	Care Value: **1.0.**
14.7%	socially involved, but passively.	Care Value: **1.0**
6.9%	receiving Occupational Therapy practice.	Care Value: **3.0**
6.9%	receiving Speech & Language Therapy practice.	Care Value: **3.0**
4.9%	walking, standing or wheelchair moving.	Care Value: **3.0**

1500 -1600		**Mean Care Value 2.4**
25%	interacting verbally or otherwise.	Care Value: **2.8**
20%	receiving Occupational Therapy practice.	Care Value: **2.9**
9%	being socially involved, but passively.	Care Value: **1.5**
9%	receiving Physiotherapy practice.	Care Value: **3.0**
8%	spent asleep.	Care Value: **1.0**
8%	walking, standing or wheelchair moving.	Care Value: **2.8**
7%	spent eating and drinking.	Care Value: **2.2**
6%	engaging with the media.	Care Value: **3.0**
4%	receiving practical, personal or physical care.	Care Value: **2.0**
4%	being assessed by the optician.	Care Value: **3.0**

3.8.2 Results of Summed behaviour codes by hour for Map 2

Table 14 shows the results of the hourly breakdown of the behaviour category codes for all subjects are presented:

Table 14: Hourly Breakdown - SCM 2

0900 - 1000		**Mean care Value 2.6**
57%	spent eating and drinking.	Care Value: **2.5.**
23.8%	interacting verbally or otherwise.	Care Value: **2.8**
7.1%	being socially involved but passively.	Care Value: **1.0**
4.7%	receiving practical, personal or physical care.	Care Value: **3.0**
4.7%	receiving OT practice	Care Value: **3.0**
2.3%	engaging in own care.	Care Value: **2.5**

1005 - 1100		**Mean care Value 2.6**
24.2%	Interacting verbally or otherwise.	Care Value: **2.8**
19.7%	receiving Physiotherapy practice.	Care Value: **3.0**
16.7%	being socially involved but passively.	Care Value: **2.0**
9%	receiving Speech and Language Therapy practice.	Care Value: **3.0**
9%	walking, standing or wheelchair moving.	Care Value: **3.0**
6%	engaged in intellectual activity.	Care Value: **3.0.**
4.5%	spent eating and drinking.	Care Value: **2.0**
4.5%	engaging in the media.	Care Value: **1.0**
3%	engaged in own care.	Care Value: **3.0**
1.5%	receiving OT practice.	Care Value: **3.0**
1.5%	receiving medical care.	Care Value: **3.0.**

1105 1200		**Mean care value 2.7**
30%	receiving Physiotherapy practice.	Care Value: **3.0**
19.1%	being socially involved but passively.	Care Value: **1.6**
16.2%	having psychological therapy.	Care Value unobtained
13.2%	interacting with others	Care Value: **3.0**
7.4%	walking and moving.	Care Value: **3.0**

4.4%	engaging in intellectual activities.	Care Value: **3.0**
2.9%	receiving OT practice.	Care Value: **3.0**
1.5%	engaged in expressive activity.	Care Value: **3.0**
1.5%	spent asleep.	Care Value: **1.0**
1.5%	receiving Speech and Language Therapy practice.	Care Value: **3.0**

1205 - 1300		**Mean Care Value 1.9**
33.7%	spent eating and drinking.	Care Value: **1.8**
23%	engaged in conversation with others.	Care Value: **1.8**
20%	socially involved but passively.	Care Value: **1.3**
7.7%	having psychological therapy.	Care Value unobtained
4.6%	receiving physiotherapy practice.	Care Value: **3.5**
1.5%	engaging in the media.	Care Value: **1.0**
1.5%	spent asleep.	Care Value: **1.0**
1.5%	engaging in own care.	Care Value: **1.0**

1400 - 1500		**Mean Care Value 2.0**
38%	spent asleep.	Care Value: **1.0**
15.5%	receiving physiotherapy practice.	Care Value: **2.6**
14%	engaging in intellectual activities.	Care Value: **3.0.**
11.3%	conversing with others.	Care Value: **3.3**
8.5%	engaging with the media.	Care Value: **1.0**
4.2%	socially involved but passively.	Care Value: **1.0**
4.2%	engaging in own care.	Care Value: **1.0**
1.4%	spent eating and drinking.	Care Value: **3.0**
1.4%	having Physiotherapy practice.	Care Value: **3.0**
1.4%	walking and moving.	Care Value: **1.0**

1505 1600		**Mean Care Value 2.3**
34.3%	engaging with the media.	Care Value: **2.9**
21.4%	receiving Physiotherapy practice.	Care Value: **3.2**
16.9%	conversing with others.	Care Value: **3.0**
11.4%	socially involved but passively.	Care Value: **1.0**
10%	spent asleep.	Care Value: **1.0**
2.9%	spent eating and drinking.	Care Value: **2.0**
2.9%	walking and moving.	Care Value: **3.0**

3.8.3 Comparison of hourly breakdown from SCM 1 to SCM 2

09.00-10.00:

In comparing this first hour it can be noted that there is a very significant reduction in the socially involved but passive category from 33% to some 7.1%. In addition the time spent talking to others increased from 8% to some 24%. The Behaviour Category Code of sleep was also not noted on SCM 2 at all during this hour.

10.00-11.00:

In this hour there was a four fold increase in the category which involved interacting with others which increased from 6% to 24% and again another very significant reduction from the socially involved but passively category which reduced from 29% to 16%.

11.00-12.00:

Again there was a substantial reduction in the socially involved but passively category from some 34% to 19% and the amount of time that individuals went to sleep before lunch reduced from 8.3 to 1.5%.

12.00-13.00:

It can be noted that people took about the same amount of time to eating and drinking but again there was a significant reduction in the socially involved but passively category which reduced from 37% to 20%. Intellectual activities also increased from 0% in the previous map to 8%.

14.00-1500:

In the hour the amount of sleep after lunch increased by more than double from 17% to 38%. The socially involved but passively also reduced from

15% to 4% as did the articulation Behaviour Category Code which changed from 31% to 11%. There was a reduction the amount of reading of magazines, newspapers and the television, however, there was an increase in intellectual activities from nothing to 14%.

15.00-16.00:

In the last hour the amount of sleeping remained roughly the same from 10% in SCM 2 compared with 8% in SCM 1. The amount of time spent engaging with media increased from 6% to 34% but the percentage of time spent in verbal interaction reduced from 25% to 17%.

3.9 Summary of participants hourly Care Values in SCM 1 and 2

A summary of the care values can be presented in the following table:

Table 15: A Comparison of Care Values for each Hour

Mean Care Values	SCM 1	SCM 2	Change
0900-1000	1.6	2.6	+1.0
1005-1100	2.2	2.6	+0.4
1105-1200	2.0	2.7	+0.7
1205-1300	1.6	1.9	+0.3
1400-1500	2.4	2.0	- 0.4
1505-1600	2.4	2.3	- 0.1
Mean Daily Care Value	2.03	2.35	+0.32

As the table illustrates there is an overall increase in care values from Map 1 to map 2 up until 14.00 hrs in the afternoon. This probably accounts for the increase in time the second group spend sleeping during this hour, and the care value for this is not higher than 1.0. Indeed, it might be said that it is more appropriate for sleep to increase just after lunch rather than having it spread across the morning. For the last hour of the day there is little difference between the two maps.

When collated together the overall mean daily care value has increased from SCM 1 to SCM 2.

3.10 Comparison of Therapy time between SCM 1 and SCM 2

A comparison can be carried out between SCM 1 and SCM 2 for physiotherapy and occupational therapy. Both of these therapies occur routinely for most patients admitted to the rehabilitation ward. Speech and Language Therapy was not included as its use will depend upon whether this is appropriate or not depending on the difficulties experienced by the patient.

The results show that the average daily amount of therapy time for the 8 patients in SCM 1 is 23 minutes for physiotherapy and 31 minutes for Occupational Therapy. The average amount of therapy received per day was some 42 minutes.

On SCM 2 the average therapy time for the remaining 6 patients was 56 minutes per patient. For physiotherapy the amount of time given has risen to some 42 minutes per person and for Occupational therapy this has reduced slightly to some 26 minutes per day. Below Tables 16 and 17 compare the amount of time in minutes spent in Physiotherapy and Occupational Therapy for the patients that took part in SCM 1 and 2:

Table 16: Time spent in Physiotherapy

Participant	Minutes for SCM 1	Minutes for SCM 2
P1	0	20
P3	0	65
P4	20	20
P5	35	40
P7	15	45
P8	30	65
Mean Total	23	31

Table 17: Time spent in Occupational Therapy

Participant	Minutes for SCM 1	Minutes for SCM 2
P1	0	0
P3	45	15
P4	0	0
P5	35	55
P7	15	0
P8	35	10
Mean Total	31	26

These two tables illustrate that the amount of therapy per person does not remain consistent and therefore it become almost meaningless, and potentially misleading, to determine amount of therapy time per day because this will obviously vary depending on the needs of the patient and the time constraints of the therapist, the latter of which may well change from day to day.

3.11 Collated Results of Behaviour Category Codes

The amount of time spent in each BCC can be expressed as a percentage of the day for all patients. Care values can also be summed and averaged for these behaviour category codes for SCM 1 and presented in Table 18 below:

Table 18: Collated results of Behaviour Category Codes for SCM 1

Behaviour Codes	% Time	Care Value
(B) Socially involved passive	29	1.3
(A) Articulation	18	2.8
(F) Eating and Drinking	12	1.5
(M) Engaging with Media	6	1.9
(N) Sleeping and Dozing	8	1.0
PHYp) Physiotherapy practice	5	2.6
(K) Walking and Moving	7	2.2
(OTp)Occupational Therapy practice	7	2.3
(SLTp) Speech and Language practice	4	3.0
(P)Personal Care	2	2.7
(O) Own Care	1	2.3
(Z) Ophthalmology	1	3.0
(MC) Medical Care	.2	3.0
(D) Distress	.2	1.0

These summated results show that 42% of the time the individuals who have been mapped is spent in a solitary fashion, they are either passively looking around at their surrounding, looking at the media in the form of TV or reading, or sleeping. It can be seen that 16% of their time is spent in therapy. However, there are also many categories which remained unused. These categories include engaging in expressive or creative activity, games, craft activity, intellectual activities, religion or sex. This indicates that apart from therapy the individuals on the ward have a minimal amount of stimulation during their day both in terms of amount and range and much of it seems to be spent disengaged from any activity.

Table 19: Collated results of behaviour category codes for SCM 2

Behaviour Category Codes	% time	Care Value
(A)Articulation	17	3.2
(F) Eating and drinking	15	2.3
(PHYp) Physiotherapy practice	15	3.1
(B) Socially involved passively	14	1.4
(M) Engaging with Media	10	2.4
(N) Sleeping and dozing	10	1.0
(I) Intellectual activities	.5	3.0
(P) Personal Care	5	3.0
(OTp) Occupational Therapy practice	4	2.9
(PSY) Psychology	3	3.0
(SLTp) Speech and Language Therapy practice	2	3.0
(O) Own Care	2	3.0
(K) Walking and Moving	2	2.8
(MC) Medical Care	.2	3.0
(E)Expressive activity	.2	3.0

This table shows that 34% of the time was spent in a solitary fashion, either passively looking around or engaging in the media. The amount of time spent in therapy is over 21%.

3.11.1 Comparison of Behaviour Category Codes in SCM 1 and 2

A comparison of what behaviour occurred during the first and second map are illustrated in the Table 39, which illustrates the changes noted in both percentage of time and Care Values.

Table 20: Comparison of behaviour category codes for SCM 1 and SCM 2

Behaviour Category Codes	Change in % of time	Change in Care Value
(A) Articulation	- 1	0
(B) Socially passive	- 15	+0.1
(E) Expressive	+ 0.2	new category
(F) Eating/drinking	+ 3	+0.8
(I)Intellectual	+ 0.5	new category
(K) Walking/Moving	- 5	+0.6
(M) Engaging media	+ 4	+0.5
(N) Sleeping	- 2	0
(O) Own Care	+ 1	+0.7
(P) Personal Care	+ 3	+0.3
(PHYp) Physiotherapy practice	+ 10	+0.5
(OTp) Occupational Therapy practice	- 3	+0.6
(SLTp) Speech and Langugage Therapy practice	- 2	0
(PSY) Psychology	+ 3	new category
(MC)Medical care	0	0

This table illustrates that the Care Value for every Behaviour Category Code has increased from SCM 1 to SCM 2. It can also be noted the patients are spending less time looking around in a passive way, this having decreased by some 15%. From being the most frequently observed BCC in SCM 1 it has dropped to 4th place in terms of percentage time spent in SCM 2. There has been a slight increase in the amount of sleep from 8% to 10%. The amount of therapy time has also increased from some 16% to 21%; although Speech and Language Therapy and Occupational Therapy have slightly reduced, the amount of Physiotherapy has increased three fold from some 5% to 15%. The introduction of new categories is also evident and the BCC of expressive and intellectual activity can be observed.

Table 21: Comparison of Mean Care Values for SCM 1 and 2 for each Participant

Participant	SCM 1 Mean Care Value	SCM 2 Mean Care Value
P1	1.60	2.40
P3	2.38	2.44
P4	1.60	2.57
P5	2.36	2.63
P7	2.73	2.11
P8	1.78	2.16
Mean Total	2.08	2.39

The table shows that the mean difference overall shows an increase of care value of some 0.31 from SCM 1 to SCM 2, and that for 5 of the 6 patients there was an increase in their care value. For some patients, particularly P1 and P4, this increase is quite marked. P7 is the only patient who has incurred a reduction in care value from SCM 1 to SCM 2.

3.11.2 Comparison of BCC of Articulation for SCM 1 and SCM 2

For the Behaviour Category Code of Articulation (A) detailed information was kept as to who the patient was talking with during the mapping sessions. This category does not cover all conversation because much dialogue is subsumed under other behaviour category codes. The BCC of **A** was therefore only used when conversation was used on its own. An analysis of this category can examine care values to see if there is a difference between SCM 1 and SCM 2.

To analyse the care values in detail a comparison can be made for a specific behaviour category code for each patient on both mapping sessions. This can only be done where a category is used sufficiently and consistently for the patient between SCM 1 and SCM 2. The only category which merited this comparison was that of articulation. The participants who were compared between the first and second map include P1, P3, P4, P5 and P8. P7 was not used here because it was not possible to compare SCM 1 and SCM 2 because on the second map there was no articulation Behaviour Category Code mapped.

Table 22: Comparison of care values for articulation in SCM 1 and SCM 2

Participant	SCM 1 Mean Care Value	SCM 2 Mean Care Value
P1	3.0	3.5
P3	2.7	3.7
P4	2.5	3.0
P5	3.0	2.9
P8	2.7	3.0
Mean Total	2.78	3.22

Another way of analysing the category of Articulation is to examine the percentages as part of the total time that each professional group talked with each participant. The information can be presented graphically in Figure 3.

Figure 3: Graph to show the percentage of articulation during SCM 1 and SCM 2

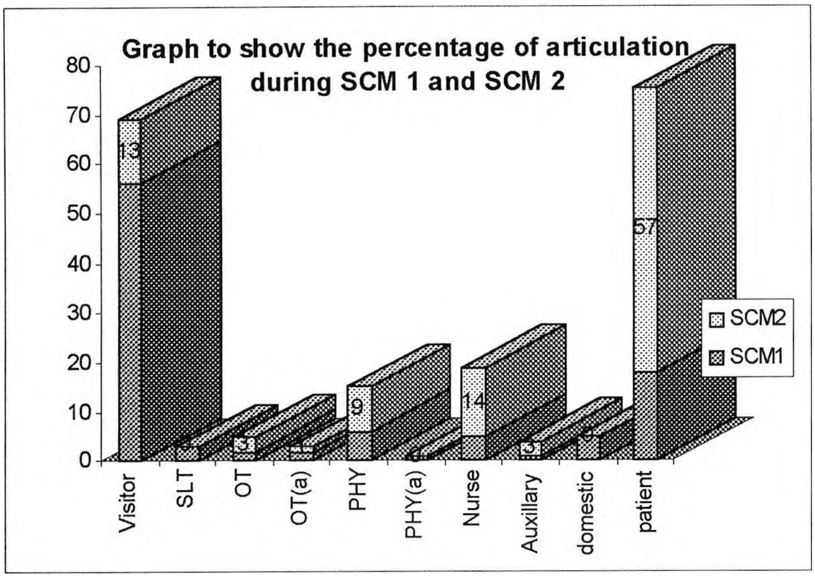


Table 23: The percentages of total time spent in articulation during SCM 1 and SCM 2

	SCM1	SCM2
Visitor	56%	13%
Speech Therapist	3%	
Occupational Therapist	2%	3%
OT Assistant	2%	1%
Physiotherapist	6%	9%
Phy Assistant	1%	
Nurse	5%	14%
Auxillary	1%	3%
Domestic	5%	
Patient	18%	57%

Figure 3 and Table 23 illustrate that there have been some changes between SCM 1 and SCM 2. The most notable change is the increase in the Articulation category for nurses. This means that nurses were talking to patients more outside of the task orientated duties. Many of the other professional groups remain very similar in the amount of Articulation provided. It is interesting to note that less time is spent talking to visitors between SCM 1 and SCM 2 and a great deal more time is spent talking to other patients.

3.12 Comparison of Care Values, (excluding Therapy) for SCM 1 & SCM 2

When analysing the results of SCM 1 and SCM 2 a concern was raised as to whether the therapy care values, which were usually a score of 3.0, were skewing the results of the mapping process. To examine this further all therapy values were taken out for each participant and new mean care value was calculated. The results are presented in Table 24 below:

Table 24: The care values for each participant during SCM 1 and SCM 2 excluding therapy

Participant	SCM 1 Mean Care Value	SCM 2 Mean Care Value
P1	1.6	2.4
P3	2.2	2.4
P4	1.4	2.4
P5	2.1	2.5
P7	2.6	2.0
P8	2.0	2.2
Mean Total	1.98	2.32

This table shows that therapy values were not skewing the results of the mapping. The results obtained are very similar to those obtained when the therapy values are included.

3.13 Results of Training Programme

3.13.1 Session 1 and 2

Staff were made fully conversant with SCM and its procedure. We looked at the importance of the psycho-social environment and how SCM serves to tap into these aspects along with the discourse analysis. They were given the results of the individual maps and a discussion ensued about patients' experiences. Staff found the feedback of the results of the discourse analysis helpful, and began to think about the nature of their interactions with patients. From the individual approach staff were shown the 'collated results of behaviour category codes for Map 1'. Some of the comments fed back to the staff for the results of SCM 1 were that:

*Overall care values are good, indicating a high standard of care
*42% of time is spent either passive, engaging in media or sleeping
*16% of time is spent in therapy
*Only 0.1% of time is spent in 'distress'
*Unused categories include: E - engaging in expressive or creativity
G- games
H - craft activity
I - intellectual abilities.

Staff were surprised to learn that the participants spent so much of their time doing nothing, and a common observation was that when they are busy they do not notice what is occurring generally on the ward. Some concern was expressed that the patients must be getting very bored, which resulted in a discussion on the potential adverse effects on their psychological functioning and how reductions in purely passive time could be made.

There was some discussion about the care values, and the therapists seemed pleased with their results. However, the Physiotherapist asked what would happen if a person was in obvious discomfort in trying to move a limb and how this might affect a Care Value. It was explained that this depended on how the situation was handled as to what Care Value was assigned. Staff discussed their reflections on possible changes some of which are listed below:

*Increase frequency of groups to see if unused categories can increase
*Increase talking time for patients with professional staff
*Make eating in the dining room as normal as possible by taking patients out of wheelchairs wherever possible
*Increase social interaction at breakfast time by having tables so that people can chat over breakfast while waiting for dressing practice
*Increase the use of volunteers to help with groups
*Make special time available to patients so that talking does not just centre around nursing tasks
*Multi-disciplinary primary nurses
*To provide plan of day for each patient which could be formulated together
*To have a system whereby explanation and education are provided
*Different professionals to sit with patients at lunchtime to facilitate conversation

The groups then carried out an exercise which asked them what they would want to experience if admitted to Samares. Some of the comments are noted below:

To have goals
To medicate myself
A chance to have outings
Structure
Dignity
Respect
Privacy
Choice
Private time
To be greeted by happy enthusiastic staff
Education

An initial explanation
To be shown around the unit
Quality
Intensive therapy
Someone to understand me
Someone to listen to me
Reassurance
Help with feeling vulnerable
Time to think
Talking to sympathetic people
Someone to relate to
An understanding approach
Someone to answer all my questions
To be looked at as an individual person
Someone there when I need them
To have my wishes and wants respected
Someone interested in me
I wouldn't want anyone to walk in on me without asking permission

We discussed the degree to which many of the experiences that people want do not in fact happen for many people on the ward. This led onto a discussion of the nature and purpose of psychological care and of its many components. We discussed the typical medical ward where many medical practitioners, including doctors and nurses, practice the view that medicine is primarily to do with physical treatment and thus how a distant impersonal style tends to dominate which depersonalises people into patients. It was explained that the task-orientated approach discourages communication and relationships under a barrier of activity. The 'THEM' and 'US' situation dominates where interpersonal distance blocks patients from expressing their true feelings. This led onto a discussion of the importance of interaction between patients and staff, and some of the results of the discourse analysis were fed back sensitively to staff. The text of some of the conversations was read out by staff members as a means of role playing to increase their understanding, and staff were encouraged to provide their comments.

3.13.2 Session 3

In this session we revisited the medical model of care and how this can protect professionals but perpetuates the 'them' and 'us' culture of care. A discussion ensued about the malignant social psychology which can occur in care settings and it was emphasised that this is, in the main, totally unintentional on behalf of care staff who are often doing an excellent job with limited resources. The video was shown and the groups were given a summary of the Personal Detractions. The video contained role plays provided by actors in care staff settings and staff were then asked to try and identify which Personal Detraction was occurring. They were then asked to observe over the course of a week what was occurring on the ward and to try and take a step back and listen to what was said. They were also given copies of an article, which appeared in a major disability journal, written by a person on their experience of a rehabilitation ward, and were asked to make observations.

3.13.3 Session 4

It was obvious across all of the groups that the session on personhood was running over into Session 4. Some staff made observations about the PDs they has observed over the previous week, indicating that they were beginning to take this issue seriously. However, very few had had a chance to read the article which was given out the previous week on a person's experience and so discussion of this was very sparse.

The first part of this session was devoted to role plays by staff of some of the personal detractions which had been noted during SCM 1. This method was particularly poignant because the Personal Detractions became real for them as something which had actually happened on their own ward and not just an example of practise elsewhere. Staff seemed to enjoy the sessions and were quite surprised at how they felt when receiving a Personal Detraction.

The role plays led on to a discussion about our attitudes and how these may influence how we behave. We examined stereotypes of individuals such as ‘politicians’, ‘pensioners’, ‘lawyers’ and ‘butchers’, and it was pointed out how negatively most people viewed being a ‘pensioner’, whose stereotype many staff described as individuals with little money who get old and have increasing risks of physical illness, and made reference to facial and bodily characteristics of getting old. By contrast, for a ‘ lawyer’ staff often talked of these individuals as having money, status, affluence and intelligence, but with an eye on the main chance. Staff were also asked to use some words to define ‘old age’, and again we noted that the negative words used far outweighed those which were positive, so we discussed how this may reinforce our stereotype. Unfortunately in all groups there was not enough time to move onto the effects of ageism on society or to see how care staff might change one aspect of their practise as a result of training.

3.14 Collated Results Of Discourse Analysis

3.14.1 Analysis of the textual dimensions of conversation

To analyse the textual dimensions of conversation the data was divided into two main sections examining the quantity of nurse-patient interaction and the quality of nurse-patient interaction (Macloed-Clark 1985). In addition, some attention was paid to the patient's contribution in the interaction. This was considered important because it has been argued that previous research has tended to ignore the patient's verbal contribution to nurse-patient communication (Jarrett and Payne 1995).

3.14.2 Quantity of Interaction

This section will include an examination of the quantity of interaction that took place in the taped conversations and will include: proportion of silence, share of conversational floor, topics and length of utterance.

3.14.3 Proportion of Silence

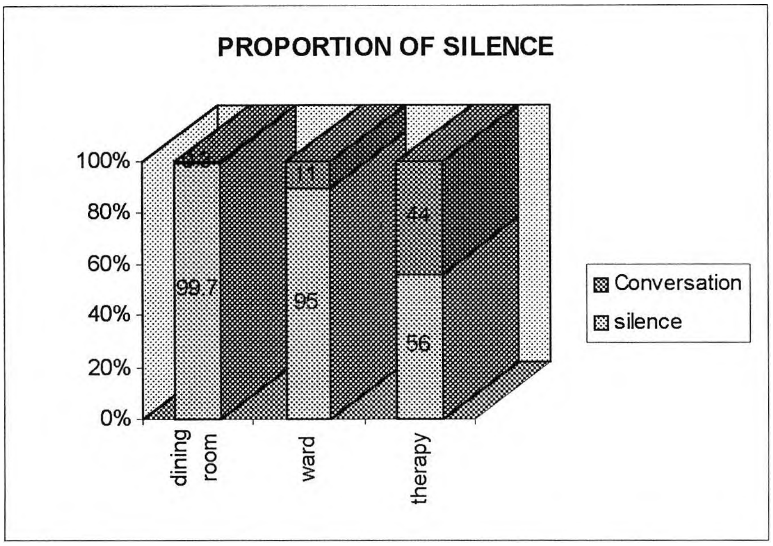
For each transcript the proportion of time spent without conversation directed towards the patient was calculated. The results for each participant are presented below in the Table 25 below. The results show the percentages of time spent in silence for each participant. The amount of time is not presented here because it has to be expressed as a proportion of the amount of time the tape was running for each individual. The results for each participant are presented below:

Table 25: The proportion of silence for each participant

Participant	dining room	ward	Therapy
P1		100%	
P2		90%	
P3	99%	98%	31%
P4	100%		64%
P5	99%		
P6	100%	99%	
P7	100%	91%	52%
P8	100%		83%
Mean	99.7%	95%	56%

The following graph on the next page, Figure 4, illustrates these results:

Figure 4: Graph to show the proportion of time spent in silence by location



This graph illustrates that in the dining room nurses directed very little conversation towards the participants and almost 100% of the time was spent in silence. When there was some interaction, which has been calculated as 0.3% of the time, it was merely a question of choice of food items. An interesting observation can also be made here in that there was no taped conversation between the participants and other patients. The proportion of the time of silence was also apparent on the ward where there was silence for 89% of the time. However, in the therapy sessions the proportion of silence was greatly reduced to some 56%.

It appears that these results do not vary according to the individuals involved because for P7 and for P3 the pattern is the same as illustrated by the following graphs.

Figure 5: Graph to show the proportion of time spent in silence for P7 by location

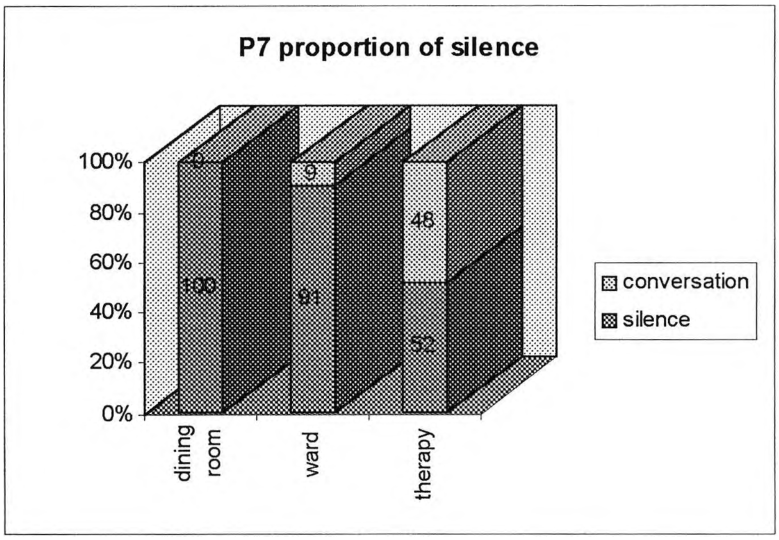
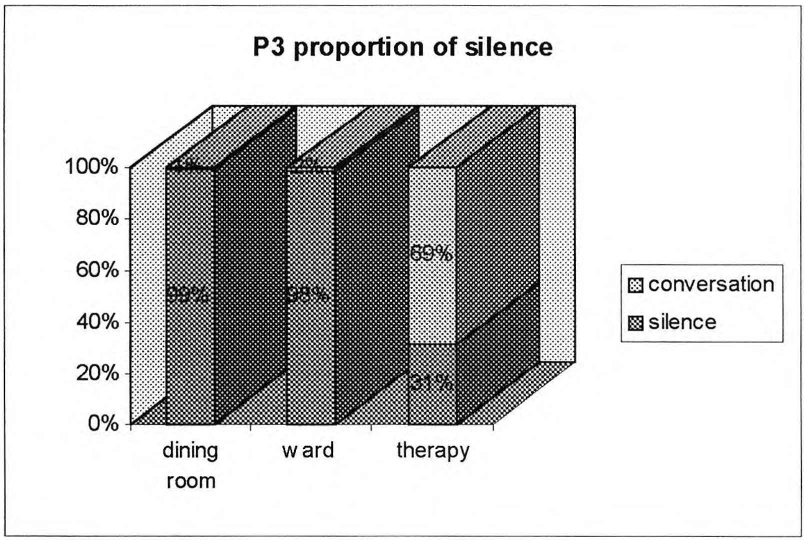


Figure 6: Graph to show the proportion of time spent in silence for P3 by location



These two graphs illustrate a similar trend to the collated results for the proportion of silence in that there is very little conversation in the dining room, slightly more in the ward, but this increases markedly in the therapy sessions.

3.14.4 Share of Conversational Floor

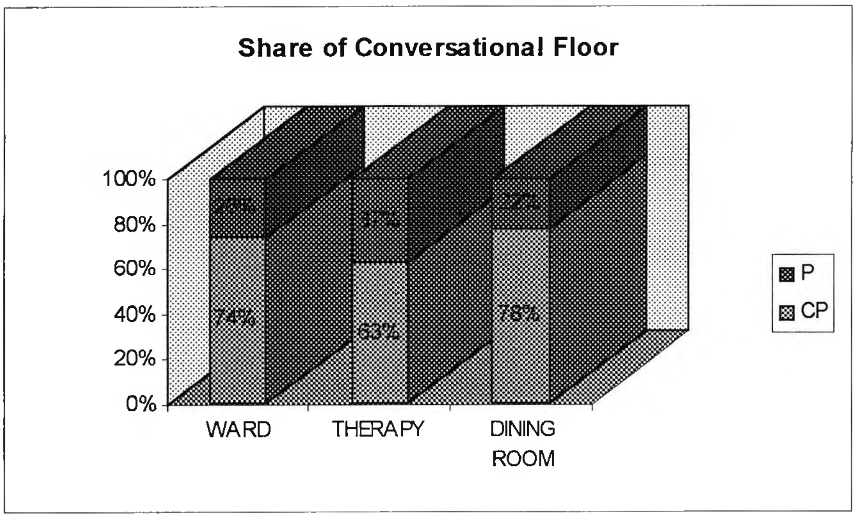
The share of the conversational floor was obtained by finding the proportion of turns by each speaker during each taped conversation and the results were collated. Percentages are used again rather than minutes because the amount would vary according to the length of tape used. Table 26 below shows the proportion of the conversational floor for the conversational partner to the patient, which was either therapist or nurse:

Table 26: The proportion of conversational floor for the conversational partner (either nurse or therapist) to the patient

Participant	Dining Room	Therapy	Ward
P1			91%
P2			70%
P3	77%	53%	70%
P4	84%	71%	
P5	72%		
P6	60%		89%
P7	93%	57%	71%
P8	66%	74%	
Means	75%	63%	78%

Figure 7 on the next page illustrates the percentages of the mean graphically and is presented below:

Figure 7: Graph to show the percentage share of the conversational floor



The collated results show that the share of the conversational floor was biased towards the conversational partner rather than the patient in all three contexts. However this difference was less marked in therapy sessions. This graph shows the participant has a greater share of the conversational floor when in therapy sessions, 37% as opposed to 22%, meaning that the nurses are taking up more of the conversational floor than therapists when in conversation with participants.

In analysing the results of P3 and P7, because their transcripts ranged across all contexts it can be seen that the share of the conversational floor indicates a similar trend for both participants. This indicates that the share of the floor for these participants is not merely a product of the individual characteristics of the person but rather that it is the context that plays a part in the amount of speech that will take place.

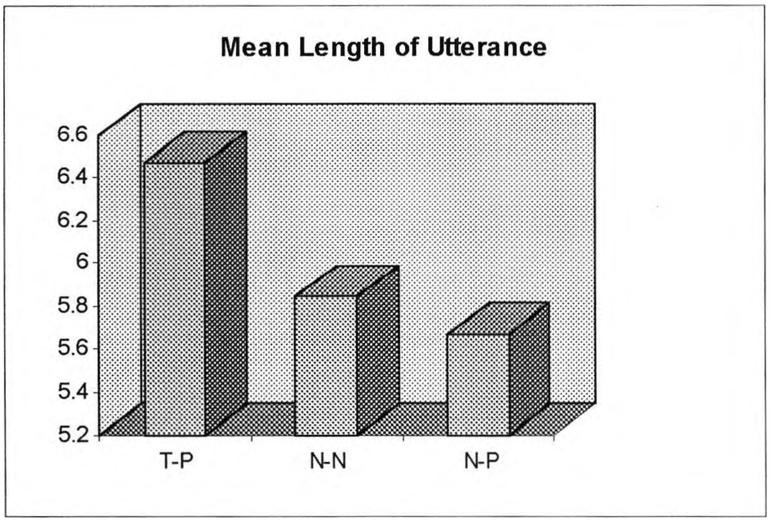
3.14.5 Length of Utterance

To analyse length of utterances the number of words per clause were counted for all individuals who were taped. This included counting the contracted copular verbs such as ‘it’s’ which would be counted as two words, and excluding repetitions. The results which are presented Table 27 below show that the mean length of utterance during the therapy sessions was 6.1 words which can be compared with a length of 5.4 between nurses and patients and 6.0 when nurses are talking to each other. Figure 8 below illustrates this point.

Table 27: mean length of utterance during therapy sessions

Participant	Nurse-Patient	Nurse-Nurse	Therapist-Patient
P1	6.5	5.67	
P2	7.22	5.88	
P3	4.17	5.36	6.95
P4	5.64	5.41	7.75
P5	5.53	7.06	
P6	5.75	6.29	
P7	5.07	4.7	5.45
mean	5.67	5.84	6.47

Figure 8: Graph to show the mean length of utterance towards patients (T-P = Therapist - Patient, N-N = Nurse - Nurse, N - P = Nurse - Patient)



3.15 Quality of Verbal Interaction

This section examined the quality of the conversations that have been taped and will looked more closely at the types of verbal interactions present in the recordings and the introduction of topics.

3.15.1 Type of Verbal Interaction:

In the analysis of the various types of verbal interactions used each verbal interaction was categorised using a method used in previous research by Thomas (1994), which has been shown to have high inter-rater reliability (>.95) and validity. However this study coded each turn the speaker took in the conversation and then examined the proportion of each type of interaction in the whole transcript, rather than time spent in each category as in Thomas' study. This meant new categories of 'greeting' and 'minimal responses' were added. Questions were subdivided into 'Yes/No' and 'Open' because it has been suggested that the class of question chosen restricts the conversational partner's reply. In addition, consideration was made of the patient's responses. The categories used in the study by Thomas (1994) are shown below in Table 28, along with those additional categories included for the present research (these categories are denoted in bold type face):

Table 28: Categories used to analyse type of verbal interaction

Giving Choice	Offering a choice to patient, e.g. 'would you like chicken or mince?'
Questions: Yes/No	Asking questions that require a simple yes or no response, e.g. 'would you like a cup of tea?'
Questions: Open	**Asking questions that expect a reply from an open range of replies, e.g. 'how was your weekend'**
Commands	Giving instructions
Explanation-simple	Routine explanations and remarks, brief answers to questions, comments on surroundings/care events/illness
Explanation-detailed	More detailed explanations of procedures, detailed answers to questions, detailed comments on surroundings/care events/illness
Encouragement	Verbal remarks associated with encouraging self-care/goals of rehabilitation/any positive behaviours
Teaching	Imparting knowledge associated with changing behaviour
Reassurance	Using reassuring words, attempting to relieve worries
Sociable	Conversation involving topics outside of care issues or the patient's condition or care
Greeting	**Routine greeting remarks, e.g. 'hello, how are you?'**
Minimal Responses	**A response given, usually only one word, that does not further the line of conversation**
Other	Verbal interactions which could not be classified within those above, or were inaudible

The type of verbal interactions by different speakers can be presented graphically on the Table 29 on the next page:

Table 29: The percentages of types of interactions between speakers

	choice	quest-ions y/n	Questions open	Com-ands	expl-simp.	Expl-det.	Teach-ing	re-assur	soc-iable	encou-rage	greet-ing	min-respo	other
n-p	3.9	28.4	6.4	11.5	30	0.5	0.1	1.9	2.9	0.5	3.8	4.2	5.0
n-n	0	16	7.2	5.3	38.9	1.7	0.1	2.4	14.4	0	1.5	6.9	5.6
t-p	0	16.6	3.2	11	25.4	3.4	2.8	6.4	10.2	7.8	0.6	9.0	2.8
t-t	0	0	0	0	0	0	0	0	0	0	0	0	0

From the table and graph below which compare staff-staff and staff-patient interactions it can be seen that:

1) Interactions from the nurse to the patient comprise mainly simple explanations, and questions requiring a yes/no response rather than open questions. The third highest category of interactions from nurse to patient is in the form of commands. There are few sociable interactions and little reassurance or encouragement.

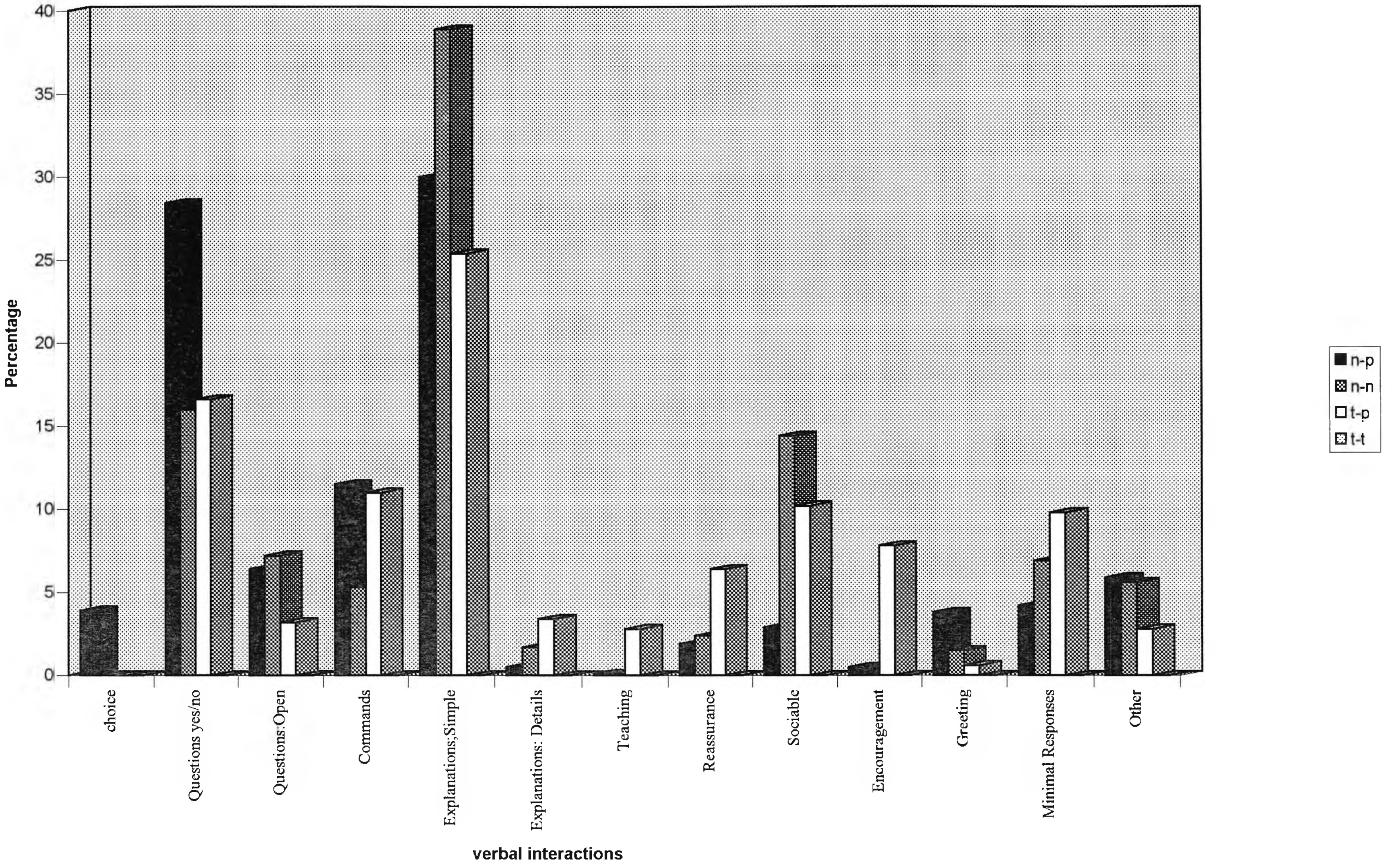
2) Therapist to patient interactions again have high numbers of simple explanations and questions requiring yes/no responses. Again the third highest category is that of commands to patients. However, there are more detailed explanations, teaching, reassurance and encouragement than from all other speakers, and high levels of sociable interactions. Indeed, with regard to reassurance nurses appear to give each other more reassurance than they do to patients.

3) There are no therapist to therapist interactions in the taped conversations. This is probably because in the majority of therapy sessions a one to one interaction is the norm and there is little opportunity to talk to another therapist in that setting. By contrast there are many

more nursing staff on the ward and therefore interactions between nurses are much more commonplace. It can be noted that nurses tend to ask each other simple questions or those which require a yes/no response as they do with their patients, but they use few commands and their interactions are much more sociable.

4) Nurse to nurse interactions show the highest levels of simple explanations, open questions and sociable interactions. Reassuring interactions between nurses are higher than between nurse and patient. Nurses give patients the most choice when compared with therapists. However, these results may be skewed because one of the contexts was the dining room and therefore this may have led to more of this type of interaction being prevalent for the nurses who do serve the lunch.

Figure 9: Comparison of staff-staff and staff-patient interactions



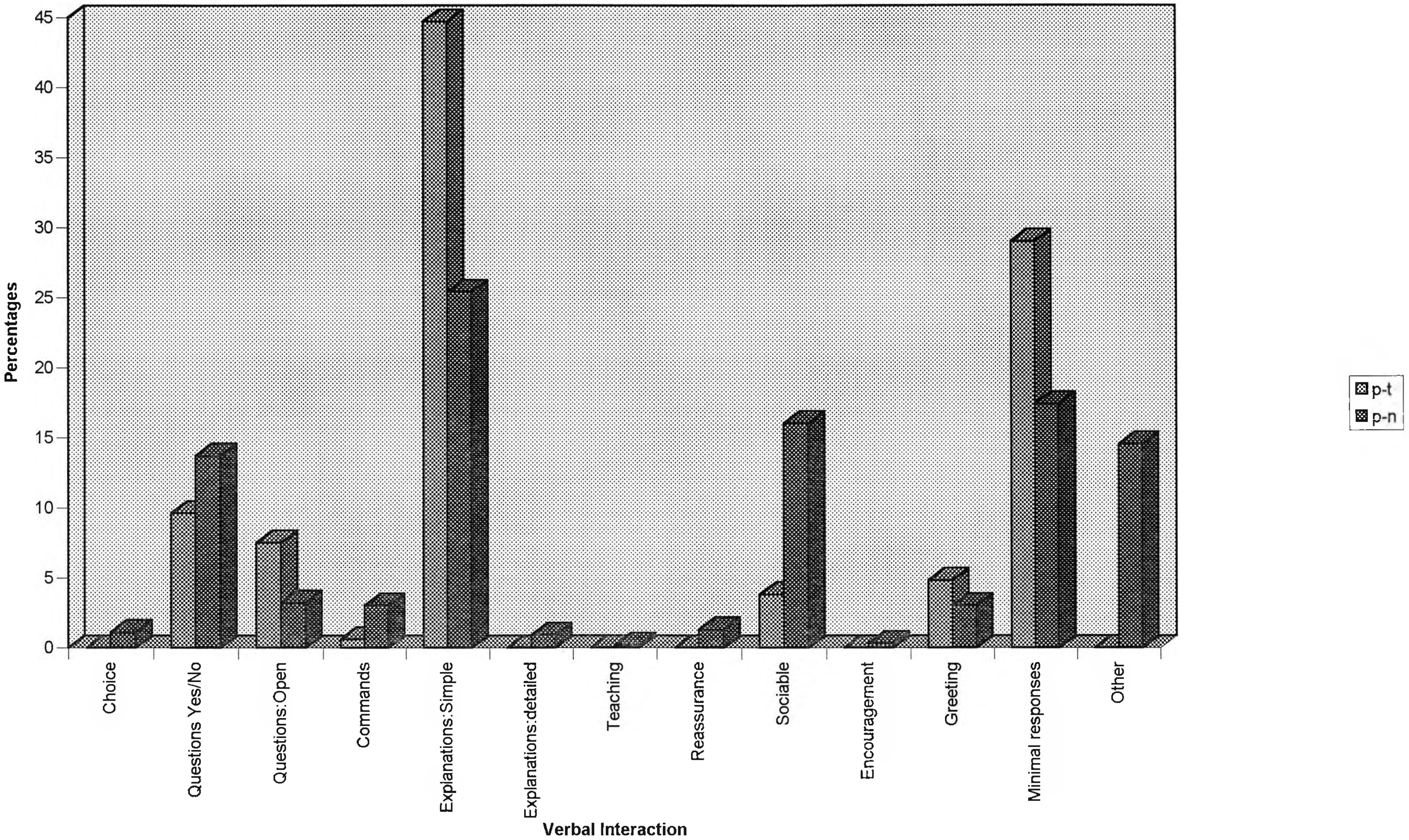
The type of verbal interaction from the patient to the nurse and therapist was analysed and the table 33 shows the results:

Table 30: Type of verbal interaction from patient to nurse and therapist

	choice	questions y/n	Questions open	Comands	expl simp.	Expl det.	Teaching	re-assur	sociable	encourage	greeting	min-respo	other
p-t	0	9.6	7.5	0.6	44.7	0	0	0	3.8	0	4.8	29	0
p-n	1.1	13.7	3.2	3.0	25.4	0.9	0.2	1.3	16	0.3	3..0	17.4	14.5

The following table (Table 54) and graph (Figure 10) presented below to compare the patient's verbal interaction with nurse and therapist show that patient's interactions towards staff members are mainly simple explanations and questions which require a yes/no response and this type of interaction is greater towards nurses than towards therapists. Sociable interactions are high and in this category the reverse is the case, in that, patients tend to have more sociable interactions with therapists than nurses. Patients only appear to ask therapists open questions because there were no open questions from patients to nurses observed. No commands from patients to therapists or nurses were noted.

figure 10: comparison of patient's verbal interaction with nurse and therapist



3.15.2 Topics Initiated

For each transcript the number of topics initiated and maintained that were not care orientated were noted. This was divided into either those initiated by the participant and those initiated by the conversational partner. On a number of occasions the patient or conversational partner made a 'sociable' verbal interaction, but this was not expanded on as a topic by the other speaker. Table 31 illustrates the topics introduced in each transcript:

Table 31: The number of topics introduced in each transcript

Participant	Dining room	Therapy	Ward
P1	-	-	0
P2	-	-	2 (P 2, CP 0)
P3	0	21 (P 12, CP 9)	1 (P)
P4	0	3 (P 1, CP 2)	0
P5	0	-	8 (P 2, CP 6)
P6	0		0
P7	0	4 (P1, CP 3)	0
P8	0	2 (P 1, CP1)	-

This table illustrates that in the therapy sessions one can see topics being initiated by both participant and conversational partner. This is particularly evident for P3 who initiates some 12 topics during the taped interaction with the conversational partner initiating 9. For the ward based setting it can be seen that the nurse has not initiated any topics of conversation above and beyond nursing orientated tasks.

3.15.3 An analysis of verbal interaction for P3 and P5

When examining the transcripts for all 8 participants it was noted that there were 2 that stood out above the rest. This was a conversation between an occupational therapist with P3 in a therapy session. The other conversation was between P5 and a domestic on the ward. From analysing these transcripts in detail it is clear that there are a number of ways they are different from the others and this can be demonstrated when examining the frequency of different types of interaction illustrated here by Table 35. Firstly, it can be noted that there are a high degree of social interactions for both participants and what is noticeable is that there is also a large number of explanations in the conversation of P3.

Table 32: The frequency of different types of interaction

Participant	choice	questions y/n	questions open	commands	explan simple	explan det	teaching	reassurance	socable	encourage	greeting	min-resp
P3	0	8	0	1	28	6	1	5	27	4	1	17
P9	0	2	0	0	5	0	0	0	83	2	3	2

Secondly, the share of the conversational floor was roughly equal; 53:47 between conversational partner and participant for P3 and 59:41 for P5. This indicates that both parties had a full opportunity to exchange conversation. Thirdly, the minimal responses are also the lowest of all the subjects, coming out at 6% for P3 and 5% for P5. Fourthly, the amount of silence is also a great deal less than the other transcripts coming out at 31% for P3 and 56% for P9. It can also be noted that the amount of topics introduced during the conversations is the highest of all participants. This shows that in the dialogue with P3 there were 21 topics outside of the immediate care environment and for P5 there were some 8 topics introduced. Lastly, these conversations show an increased length of utterances between the CP-P. This rises to 9.5 for P5 and 7.0 for P3.

3.15.4 Comparison of 3 transcripts to compare interactions between members of the multi-disciplinary team

In order to compare one-one conversations with different professionals 3 transcripts were pulled out for examination. The transcripts include a bowel intervention by a nurse to P2, an Occupational Therapy session with P3, and a Speech and Language therapy session with P7. A number of variables were considered and presented in Table 33 below:

Table 33: A comparison of transcripts between an Occupational Therapist, a Speech Therapist and a Nurse

OT session with P3	SLT session with P7	Nurse session with P2
Question: 9 y/n	16 y/n 13 open	11 y/n
Command: 0	17	3
Statement: 87	65	31
Topics: 12 (P) 9 (OT)	1 (P) 3 (SLT)	2 (P) 0(N)
Floor Share For OT: 47%	For SLT: 61%	For Nurse: 70%
Silence: 5 mins	92 secs	22 mins

Table 33 above shows some differences between the interactions which have been analysed. Of most note is that the nurse did not initiate any topics outside of the immediate task whereas both therapists took this opportunity. It can also be noted that the nurse had the majority of the conversational floor whereas with the therapists the share was more equal. There is also a large of amount of time spent in silence during the interaction. It can also been seen that the therapist make greater use of statements than the nurse.

3.16 Contextual Dimensions

In analysing the conversations there were a number of themes which seemed to recur which are worthy of note and can be separated under a number of headings:

3.16.1 'Them and Us'

At times during the transcript there was a strong feeling of 'them' and 'us' on the ward. At these times it was clear that the nurses were a group that were totally different from the patients. A number of conversations illustrate this point:

A background conversation between nurses during the transcript of P4:

159 BC:N: *Alison*
160 BC:N: *yes*
(1.0)
161 BC:N: *breaks*
162 BC:N: *yes (2 sylls)*
163 BC:N: *breaks (.)*
(1.0)
164 BC:N: *you and me (are the same)(.) leave them all to it*
165 BC:N: *leave them all to it*
167 BC:N: *I think that's a good idea*

In this conversation the nurses show their solidarity to each other and group the patients together as if they were unimportant.

A conversation between nurses about P5 during the transcript

33 BC:N:4 *you know it's the sort of things that we take for granted*
34 BC:N:3 *yes*
35 BC:N:4 *I mean you would stand up and pull that back*
36 BC:N3 *[yes(.)that's right(.)yes(.)*but they can't can they*
37 BC:N:2 *so therefore(.) okay darling?*
38 P: hhh

This conversation implies that the nurses are the 'normal' ones and the patients are 'damaged' and therefore very different; this accentuates the 'them' and 'us' feel to the conversation.

A conversation between nurses and P6:

23 BC:N: *yesterday (for me) (.) if you hurt one of our girls by messing around I'll be so annoyed I can't even tell you*
25 BC:N: *don't hurt none of our girls' backs when they've got little children to go home to*

This conversation sounds as if the collective group of 'girls' are a group that is separate from the patient and this creates a feeling of staff members ganging up on a patient.

3.16.2 Labelling

This occurs quite often in the transcripts when the patients are grouped together in one phrase. Examples of this include:

transcript of P5

119 BC:N:4 *[did we get*the dysphagics*

transcript of P4

51 BC:N: *we've got fish for Mrs (1sylls) and we've got two dysphagics*

Here patients are referred to by their conditions rather than as a people, almost as if this takes priority as the most relevant factor about the patient.

3.16.3 Ignoring

There were some examples of where the participant was ignored by the nurse who proceeded to talk as if they weren't there or talked over them. Some examples of this are as follows:

transcript from P7

63 BC:N:1 *just hold onto her back somewhere(.)trousers or something*
64 BC:ST: *righty ho okay then*
65 BC:N:1 *yeah she'll yeah she's just*
66 BC:ST: *do that then*
67 BC:N:1 *catch her if she falls over that's all*

In this conversation the participant is being spoken to almost as if she is an object and don't refer to her even though she is present.

transcript from P3

26 BC:N:3 *that's Mrs Page here is it? Oh (dear) (.) hello I haven't*

met you how are you

In this conversation the nurse did not think to go up to the patient and ask their name but rather pointed to them and asked another nurse.

transcript from P5

29 BC:N:3 *hold on to the table (.) that's alright*
30 BC:N:2 *see he has to think of things to do himself*
31 BC:N:3 [himself*yes
32 BC:N:2 *and if he cannot(.)(see he can't) that's when you have the right(.)*

In this conversation the participant is referred to in the third person when he is present and can hear the conversation between the nurses.

3.16.4 Interruptions

On a number of occasions a member of staff was with a patient and they were interrupted. In these situations the patient is ignored and there is no apology. For example:

transcript from P2

148 CP:N: *let's slip these off so then I can (4sylls)*
149 BC:N:7 *Jo have you got the keys?*
150 BC:N:1 *yeah*
151 BC:N:7 *could I um(.) are you?*
152 BC:N:1 *do you wanna just could you just grab me two er a (3sylls) out of the (3sylls) please*

In this example the patient is having a personal examination and the nurse simply interrupts and asks for the keys without any explanation to the patient. At 151 she is talking to the nurse to ask if she is okay rather than the patient. It is also interesting to note that other nurse does not make any apology to the patient either.

In another transcript for P4 it can also be noted that the nurse interrupts a dressing practice session and proceeds to greet the OT but completely ignores the patient.

There is one good example from the transcript for P8 where the person makes a more suitable interruption; however, it can be noted that on this occasion the domestic was the person who interrupted the session.

transcript from P8

114 CP:D: *hello(.)(2sylls) calling(.)Ernie(.) how are you?(.)can I just give um (.) are you decent?(.) can I give you this?*

3.16.5 Ignoring cues

On a number of occasions it can be noted that the nurses did not modify their language when a repair was needed. For example:

transcript from P3

6 CP:N:1 *it was edible?*
7 P *(2 sylls)*sorry?*
8 CP:N:1 *it was edible?*
9 P *I don't know what*
10 CP:N:1 *it was edible*
11 P *it I was the best meal of the of the I think the whole time I love it so much a lovely cup of coffee and some brown toast*

In this conversation the patient was obviously no understanding the meaning of the word ‘edible’ but the nurse did not repair her conversation but carried on regardless, perhaps assuming that the breakdown occurs because the person has a hearing problem due to their age.

transcript from P5

52 BC:N:1 *sleepy?*
53 BC:P:8 *hmmm?*
54 BC:N:1 *sleepy?*
55 BC:N:8 *sleepy?*
56 BC:N:1 *yes sleepy(.) you're a sleepy head*
57 BC:P:8 *hmm hmm*

In this conversation the second ‘sleepy’ phrase is simply said louder rather than rephrasing the question with more information. Again an assumption seems to have been made about the person’s hearing abilities.

transcript from P 6

27 BC:N:1 *what would you like to eat(.) can you hear me?*
28 BC:P:6 *ahhh*
29 BC:N:1 *can you hear me?*
(2.0)
30 BC:N:1 *no (.) he can't*
(6.0)

3.16.6 Unresponded to

transcript from P 2

142 P: *=well then I might dirty the bed and then I'll be in trouble(.)won't I?*
143 CP:N:1 *no I won't shout at you (.) I'm kind I don't shout at people*

In this question the participant is asking for reassurance and although the nurse tries to provide it she makes a joke out of it rather than addressing the concerns seriously.

transcript from P2

101	P:	*well they(.) the physiotherapy young lady told me it's not really a stroke I its what they call one=*
102	CP:N:6	*but=*
103	P:	*=that's what (3 sylls)*
104	CP:N:6	*[you've been having * you've had you've been having little accidents like that since*

Here the patient obviously wants to talk about the stroke and perhaps to seek further clarification but the nurse remains focused on her direction and task.

Transcript from P2

132	P:	*that's another thing I forget people's names*
132	CP:N:3	*there's a lot of us around I'm afraid*

Here the nurse is expressing some concerns about her memory and the nurse laughs it off with a little joke and has not really responded to the person's concerns.

3.16.7 Stereotypical assumptions

Some older people, as much as any other individuals, may have communication needs such as sight or hearing impairments. However, it is all too easy to lump a section of society together as 'the elderly' and assume that all of them have the same communication difficulty. With this in mind speakers have been shown to modify their speech when communicating with 'the elderly' (Ryan et al. 1986). In the following example the nurse has made an assumption, an assumption that the person is hard of hearing:

transcript from P6

31	BC:N:1	*can you hear me?*
32	BC:P:7	*yeah oh yes*
33	BC:N:1	*yes*
34	BC:P:7	*very well*

In this conversation it can be seen that the nurse it assuming that a number of patients are unable to hear her. In fact P6 has expressive problems and this was why there was a limited response. For P7 he gives a strong response to the nurses question and it sounds as if he is almost insulted that she should ask such a question.

transcript from P7

58	BC:N:2	*Doris?*
59	BC:P:2	*(3sylls){laughs}*
60	BC:P:2	*oh oh (.)you mean water?*
61	BC:N:2	*yes yes water=*
62	BC:P:2	*=oh water's very*
63	BC:N:2	*no(.)are you(.)drinking enough water?*
64	BC:P:2	*[yes*yes (.)I think so*
65	BC:N:2	*can(.)you(.)hear me?*
66	BC:P:2	*pardon?*
67	BC:N:2	*can you hear me?(.)are(.)you(.)drinking(.) enough liquid?*
68	BC:P:2	*yes well I've never watered very(.) big water drinker*
69	BC:N:2	*alright(.)well even tea(.)just make*sure that you keep*
70	BC:P:2	*[oh yes*

In this conversation the nurse does attempt to repair the conversation and rephrases the question and the participant responses. However, the nurse seems to want to ask the question again despite having an answer and this obviously confuses the participant and the nurse assumes this is due to difficulties are in relation to a hearing problem.

CHAPTER 4

4.0 Development of the SCM tool and Manual

4.1 Amendments to SCM

After using the SCM tool as described in SCM 1 and SCM 2 a re-evaluation of the techniques was carried out in the light of the results. The refinement of certain aspects of SCM are described below:

4.2 Amendment of Behaviour Category Codes

During SCM 1 and SCM 2 it became apparent that the data was driven by the professional therapy rather than by the activity or behaviour. On re-evaluation it was clear that the tool was liable to criticism in this respect for a number of reasons. Firstly, mapping in this way ignores the fundamental basis of this method which has at its roots the concept of 'personhood', whereby the individual must always be the central focus of any observation. Secondly, this tendency to overemphasise the therapies rather than the person and what they are doing has a long history in rehabilitation work and has served to encourage separateness and division in the team approach; for example, it is too simplistic to assume that the only time a person has physiotherapy is when they are with the physiotherapist, when in an ideal rehabilitation setting other professionals would become involved in carrying through the work of the physiotherapist. This rarely happens in practice, but any observational tool must take care not to fall into the trap of concentrating on the therapy rather than the activity. Thirdly, mapping by therapies fails to record much information on activity because it is subsumed under the sub-heading of a professional within the multi-disciplinary team; for example, when Occupational Therapy was mapped the person could have been doing a whole range of behaviours such as dressing practice, using the computer or cooking which would have just been mapped as 25 minutes in OT. As the purpose of the tool is to evaluate the experience of the person it is important to map what activity occurred rather than by reference to which professional was involved. Lastly, during mapping it was also very difficult to differentiate between assessment, practice and teaching, as many of these activities were occurring simultaneously.

As a result of these criticisms it was decided that activities which were of a therapeutic nature would be recorded under existing behaviour category codes, but prefixed with a **T** (therapy), instead of using the category codes for Occupational Therapy, Physiotherapy, Speech and Language Therapy, Nursing, Psychology and Medical Care; For example, if a patient was using the computer with the occupational therapist, this would now be coded as **TIot** (Therapy, Intellectual with an Occupational Therapist) with the appropriate care value. However, it is important to note that in order to add **T** in front of a behaviour category code the behaviour must be directly related towards the achievement of a goal as otherwise, the term 'therapeutic' could refer to the nature of many other interactions that occur in a ward environment. The details of how this information will be recorded is clarified in the next section on the 'addition of goals' to the SCM method.

As a result of losing the category of Physiotherapy, **J** (joints) was reinstated. After talking to physiotherapists it was decided that **J** should be divided into two parts that of **Ja** which is active exercise, in that the person is able to move independently and **Jp** which is passive exercise so that the person has to be physically assisted to move; For example, the code will be **TJaphy** if a patient was doing some active exercise with the physiotherapist. The recording of transfers was also felt to be such an important area in rehabilitation therefore, **T** was denoted as a transfer either to sitting or vice versa. Therefore, if a therapeutic transfer was being carried out with a physiotherapist this would be denoted as **TTphy**.

Similarly, after consultation with an occupational therapist it was decided that it was necessary to include a category to record domestic activities such as housework or cooking and these are to be denoted by the category of **W** (work). It is vital that this activity is recorded because rehabilitation aims to help a person restore the skills necessary for everyday living. The category of **K** (kum and go) was subsumed under **L** (locomotion). This new category needed to be expanded so that activities such as walking (**LW**), standing (**LS**) and wheelchair moving (**LWh**) could be determined from each other. This was important in the absence of a Physiotherapy category. However, if a patient was being helped to walk by a physiotherapist during a physiotherapy session, it was felt most appropriate that this would be coded as **TLWphy**.

It was also decided that it would be important to have some means of mapping meetings that take place between the professionals and the patient, with or without their family to examine progress. Although this had not been observed during the SCM, it would be important to have a category to record this important event. This would be denoted by the category of **K** (kuming together). The category of **S** which is activities related to sexual expression was not mapped in SCM 1 and 2. It is possible that in a rehabilitation setting this BCC is not quite so relevant as in a dementia setting. Therefore, it was decided that this BCC would be erased. However, if activities of this kind were observed the mapper could write under the miscellaneous code of **Z** which is the category for behaviours that fit no existing category. It was also decided that the BCC of **S** referring to the direct engagement of the senses may be more appropriate in a rehabilitation ward. However, further experience with mapping in this setting is required to establish the utility of this BCC in the future.

4.3 Addition of Goals

Following SCM 1 and SCM 2 it became evident that there had been no attention paid to one of the central features of rehabilitation which is to plan, set and carry out goals. It was felt that SCM would be an ideal way to capture some information on when work on goals was being carried out and which professional was involved with the patient in this activity. It would also be interesting to observe whether there was any carryover of goals between professional groups and to see if goals were attempted outside of specific therapy sessions. As goals are such an essential feature of rehabilitation then some opportunity to record them is essential in any tool which evaluates the rehabilitation process. In order to examine this further a small pilot study was carried out on five individuals to look at goals in more detail. Unfortunately only two participants from the original trial could be evaluated, namely P3 and P5 because the rest had been discharged, so three subjects who had experienced a stroke were picked at random from the ward. The researcher ascertained from each member of the multi-disciplinary team the goals which had been set for each participant for that week. These goals were incorporated onto a form and numbered. A table was then devised to allow the researcher to record which goal had been carried out by whom and when. Each person was observed individually for one day from approximately 9.00 am to 4.00pm which was broken down into five minute intervals. For each individual the percentage of time the individual spent working towards achieving goals was calculated. Goals were then further broken down as to whether the person carried out the goals independently, whether they were carried out by the professional group which had set them during a therapy or nursing session, or whether there was carryover where activity towards goals set by one professional was carried out by another. In addition, given that in the majority of cases it is hoped that a person will return home with a relative who may assume the role of carer, it was thought important to include a category to record when the carer becomes involved in the achievement of goals during the mapping sessions. The results of the goal mapping are presented:

4.3.1 Goals set by therapists for P3

P3 is a 82 year old lady who had stroke resulting in left hemiplegia and left hemianopia and the following goals were set on 30.3.98:

Nursing Goals
1.To walk independently with a stick
2.Pain relief to be resolved
Occupational Therapy Goals
3.To make a splint for her wrist and assess its effectiveness
4.To be able to make a cup of tea safely in the kitchen
5.To work on gentle functional activities for her left hand (fine motor movement)
Physiotherapy Goals
6. Walking with guidance only - no hand needed on her arm.
7 Transfer short distances on her own (around her bed area)

Table 34: Goals mapped for P3

The table below shows a summary only of the times when activity towards goals was observed rather than incorporating a large number of empty boxes.

Place									
Time	10.20	11.30	12.40	3.30	3.35	3.40			
Goal no.	1	5	6	7	4	7			
staff	I	I	N	OT	OT	OT			

Key for staff:
Nurses = N
Physiotherapist = PHY Physiotherapy Assistant = PHYa
Occupational Therapist = OT Occupational Therapy Assistant = OTa
Speech and Language Therapist = SLT
Doctor = DR
Clinical Psychologist = PSY Clinical Psychology Assistant = PSYa
Carer=C
Independently = I Other = OTH

4.3.2 Summary

10% or 30 minutes of P3's day was spent carrying out goal related activity, of which one third was carried out independently and there was a 10% carryover when a nurse carried out a physiotherapy goal. The remainder of the time was spent working on goals within therapy sessions.

4.3.3 Goals set by therapists for P5

P5 was a 66 man who had a stroke with a loss of grey/white matter on the right side and the following goals were mapped on 3.4.98.

Nursing Goals
1. To walk with one person
Occupational Therapy Goals
2.To successfully transfer from the seat of a car
3.To continue to work on activities to improve attention to the left side
Physiotherapy Goals
4. To improve standing balance.
5. To improve the quality of his gait
6. To mobilise with a quadropod and bandage with 2 nurses
7. Posture - to be transferred into an armchair with a lumbar roll at his back, check body alignment
8. Decrease spasticity - pillow always under his left arm
9. To try to get his wife more involved with car transfers
10.Decrease spasticity in lower limb

Table 35: Goals mapped for P5

Place									
Time	1.50	1.55	2.00	2.05	2.10	2.15	2.20	2.25	2.30
Goal no.	6	6	4,5	4,5	4,5	10	10	10	10
staff	PHY	PHY	PHY	PHY	PHY	PHY	PHY	PHY	PHY

4.3.4 Summary

15% or 45 minutes of this person's time was spent working on goals and all of this was achieved in a therapy session.

4.3.5 Goals set by therapists for P9

P9 was a 60 year old man who had a stroke resulting in a right hemiplegia and the following goals were mapped on 2.3.98

Nursing Goals
1. To reduce blood pressure via medication

Occupational Therapy Goals
2. To aim towards independence for top half washing and dressing
3. To assess lower half dressing

Physiotherapy Goals
4. To have leg put up on a foot stool intermittently (1/2 hrs up, couple hours down)
5. To maintain a dynamic sitting position
6. To try to reduce swelling in right upper limb (and nurses - tubi-grip on arm, Ted stocking
7. To try and facilitate hip extension
8. To try and get trunk control in standing
9. Movement in right leg by weight bearing
10. Improving standing balance
11. Position correctly in chair - maintain alignment

Speech And Language Therapy Goals

12 To sort out thematic roles (subject/verb/object)

13. To use a lite-writer to access initial letter cues

Table 36: Goals mapped for P9

Place								
Time	9.00	9.05	9.10	10.25	10.30	10.35	10.40	11.00
Goal no.	3	3	1	6	6,12	9,10, 11	9,10, 11	3
staff	N	N	N	PHY	PHY	PHY	PHY	PHY

Place								
Time	11.05	11.10	11.15	11.20	2.05	2.10	2.15	2.20
Goal no.	13	13	13	13	5	5	5	5
staff	SLT	SLT	SLT	SLT	N	N	I	I

4.3.6 Summary

23% of this person's day or some 80 minutes was spent in goal directed activity. Just over half of this was during therapy session. There was a 7% carryover during which time a nurse carried out the physiotherapy goals. P9 spent some 3% of his time attempting to carry out one of his goals.

4.3.7 Goals set by therapists for P10

P10 was a 63 year old gentleman who had experienced a stroke which damaged the left hemisphere of the brain and the following mapping of goals took place on 1.4.98

Nursing Goals
1.Monitor fluids (in and out)
2.To transfer with one
Occupational Therapy Goals
3. Aiming towards independence for top half washing and dressing.
4. To start discussing with the family about the home situation
Physiotherapy Goals
5.To teach his wife how to transfer him
6.To achieve a more independent sit to stand
7.To get active contraction on the left hand side
Speech And Language Therapy Goals
8.To try and develop use of the McCaw
9. Forced choice in selecting food and drinks

Table 37: Goals mapped for P10

Place								
Time	9.30	9.35	9.40	9.45	9.50	9.55	10.00	10.05
Goal no.	3	3	3	3	3	3	3	3
staff	OT	OT	OT	OT	OT	OT	OT	OT

Place					
Time	10.10	10.15	10.20	10.25	10.30
Goal no.	3	3	8	8	9
staff	OT	OT	SLT	SLT	SLT

4.3.8 Summary

For P10 23% of the time or just over one hour was spent working on goals and this was all carried out in the therapy sessions.

4.3.9 Goals set by therapists for P11

P11 is a 59 year old man who had a stroke with a right hemiparesis whose CT scan also showed brain atrophy and the following mapping took place on 31.3.98

Nursing Goals
1.Monitor fluids in and out
2.To monitor blood pressure sore on his buttock
Occupational Therapy Goals
3.To reassess his seating
4.To assess his perceptual skills
5.Aim towards independent washing, dressing and grooming of top half of body
6.To encourage functional use of left upper limb
Physiotherapy Goals
7.To teach person transfers on ward
8. Maintain an hour on tilt table
9.Gain active movement
10.Maintain length of left hamstring
11.To stand in alignment with 3 people
12.To be able to throw a ball with the left hand on instruction
Speech And Language Therapy Goals
13.To continue assessment
14.To develop attention, listening and keeping to task

Table 38: Goals mapped for P11

Time	10.15	10.20	10.25	10.30	11.15	11.30	11.35	11.40	11.45	11.50	2.20	2.25	2.30	2.40	2.50	2.55	3.00	3.45
Goal	4	4	4	4	8	8,10	8,6,10	8,6,10	8,6,10	8,6,10	3	6	11	11	11	11	11	5
staff	OT	OT	OT	OT	PHY	PHY	PHY	PHY	PHY	PHY	PHY	PHY	PHY	PHY	PHY	PHY	PHY	I

4.3.10 Summary

P11 spent 28% of the time in goal directed activity and some 99% of this was in therapy sessions.

4.3.11 Collated results of goal directed behaviour

When the results of the five patients are collated it can be calculated that on average 20% of the time was spent in goal directed activity. However the time spent in this activity did vary from some 10% -23% of a person's day. There was also very little carry-over from the therapists goals to the general nursing environment. A summary of the results shows that over three quarters of the whole time was spent achieving goals in therapy, which suggests that whichever therapist set the goals appears to be the one to carry them out. The results follow a similar pattern for four out of the five patients mapped, however, there are a few exceptions where, in the example of goal mapping for P9 a member of the nursing team carries out an OT goal for 5 minutes and a physiotherapy goal for 15 minutes. These instances should not be exceptional but routine because if rehabilitation is to have most chance of success, therapy needs to continue outside of therapy sessions so that therapy does not become an isolated activity but one that encompasses a large proportion of a person's day.

To quantify behaviour is a specific purpose of goal setting, but it can be seen that the goals used for the mapping sessions were often very vague. For example, For P9, Goal 3 which is to 'aim towards independence for top half washing and dressing' is very general, which could make it difficult for another member of the team to carry over the goal set for the individual because it is too vague. This would be particularly pertinent at the weekend when the Occupational Therapist does not work and therefore dressing practice is done by the nursing staff. Another example of a vague goal is a Speech and Language Therapy Goal 9 for P10, which is to ‘to try and develop use of the McCaw’, rather than being specific and stating which aspect of the McCaw is being taught. However it is important to note that on occasions it may be difficult to map a specific goal as this may be a one-off event such as Goal 4 for P11 which is ‘to assess his perceptual skills’. It may be important to note these when mapping a person’s experience and more mapping is required to be able to comment on the frequency of this event and its implications further.

4.4 Amendment of Rules

Following SCM 1 and SCM 2 it was felt that there needed to be a number of amendments to the rules, particularly in relation to the behaviour category of **A** (Articulation). During mapping there was felt to be a gap about information relating to articulation. The rules stated that articulation is only mapped when a Type 1 behaviour is not occurring; for example, if a participant was in the category of F which means they were eating and drinking and this was coded at a +3 , it can be difficult to know, when analysing the results of SCM, whether the person was socially interacting with others at the same time (therefore providing a high care value) or eating a meal with a great of deal of enjoyment but with no social interaction at all. Taken to its limit a participant could appear not to have spent any time in articulation at all during a day because whenever social interaction occurred it was in the context of some other activity which was recorded to the exclusion of articulation. This result occurs because SCM 1 and SCM 2 adopted the same rule as applies to DCM whose first rule states an order of precedence when assigning behaviour category codes which is as follows:

1.Type 1 categories (EFGHIJLMOPRSTX)

2.K
3.Type 11 categories (ABCDU)
4. N

Because articulation is a Type 11 category it will only be recorded in the absence of a Type 1 behaviour occurring. So if any Type 1 activity is taking place **A** will not be recorded even if Type 1 is secondary; for example, if a person was picking at food whilst enjoying a meaningful conversation it is the category of **F** which would be mapped. This does not seem sensitive enough to describe a person's total experience it is felt that this rule needs to be amended for the tool to be of value in stroke rehabilitation. Therefore, it was decided that Articulation should be assigned a Type 1 category.

In addition, Rule 2 also has to be eliminated in SCM because the category of **K** no longer refers to 'Kuming and going'. In DCM this category was not given the priority of a Type 1 behaviour because it was, in the main, easy for a person with dementia to move from one place to another whereas for a person who has had a stroke the ability to regain movement is one of the central features of rehabilitation. The category of **K** was therefore subsumed under the behaviour category codes which involve movement. In SCM the category of **K** has a completely different and refers to 'kuming together' for the purpose of a meeting.

Lastly, it was felt that because mapping was attempting to look at goals in relation to a behaviour a situation could arise when a goal was noted but the behaviour was not mapped because it had not occurred for the larger part of the five minute period. Therefore, it was decided that all Type 1 behaviours would be mapped that occurred in a five minute period.

In summary, the new rules for SCM are as follows:

Rule 1

The order of precedence when assigning behaviour category codes is:

1. Type 1 categories (A,E,F,G,I,J(a/p),K,L(w,s,wh),M,O,P,R,S,T, W,X)
2. Type 11 categories (BCDU)
3. N

This new rule states that all Type 1 categories have equal value and are mapped within a five minute period. If a Type 1 behaviour does not occur within the five minutes then the behaviour mapped becomes a Type 11 category and all Type 11 categories are mapped.

Rule 2

Any Type 1 behaviour which is occurring in a therapeutic setting should be preceded by **T** for example, if a patient is being helped to walk by a Physiotherapist, it would be recorded as **TLWPhy**.

Rule 3

All behaviour category codes are denoted by the staff member involved if this is observed.

Rule 4

Any significant information lost in applying these rules should be described under notes.

4.5 Amendment of Care Values

To measure quality of care DCM utilises Care Values. This may be more appropriate for individuals with dementia, who rely on others to provide their total care. For example, the person may have been placed in a residential environment because they are no longer able to meet their own needs and with no hope for them ever doing so in the future. Although individuals might initially come into stroke rehabilitation in a similar state of dependency, their rehabilitation is about maximising independence, and therefore as people get better it is no longer appropriate to solely talk about quality of care that they have received. As independence is developing one would expect stroke patients to be taking part in activities increasingly of their own volition; for example, if a person is reading a book it would be inappropriate to talk about a care value when it is a solitary activity that does not depend on anyone else for enjoyment. This is to a large extent down to the individual to derive their own sense of pleasure or satisfaction. Care value also implies that a person's quality of care is completely contingent on others and therefore it is care which is being assessed which is not so appropriate for stroke rehabilitation where we are trying to capture a person's experience.

Whilst stroke and dementia are similar in that there is a degree of cognitive impairment, the fundamental difference is that wherever possible stroke patients are rehabilitated towards independent living, whereas, in dementia a person is admitted into a care setting as their home and it is not expected that they will leave because a person generally declines as the dementia progresses. It would therefore be more appropriate to talk in terms of 'experience values' (EV) rather than care values (CV) because in measuring someone's experience in stroke rehabilitation we may not necessarily be measuring their care. In this context it is important to consider the usefulness of the DCM care score tables in stroke rehabilitation. One example of the individual care score table is provided below:

Table 39: Individual Care Score Table

3.0 and above	excellent
2.2-2.9	very good
1.5-2.2	good
0.8-1.5	fair
0.7 and below	much improvement needed

Although this provides a useful starting point for evaluating the meaning of a person's care value the validity of using a table designed for individuals with dementia to individuals who have had a stroke is questionable, given that in the field of stroke rehabilitation the structure of the day is very different; for example, individuals who have suffered a stroke have one to one therapy on a daily basis may automatically enhance care value scores but a person with dementia may spend a large proportion of their day without a one-to-one interaction and so the potential for similar care value scores diminishes. In addition, the care score table is based on norms from a dementia population, and therefore it was questionable as to whether these norms applied to stroke. It may therefore more appropriate in stroke rehabilitation for the care value score tables to be based on whether an experience was worthwhile and valuable from the point of view of the patient rather than representing excellent care from the point of view of the input from the staff based on the ward.

4.6 Revised version of Stroke Care Mapping

As a result of the difficulties which were noted, SCM has been amended to incorporate the recommended changes, and a Table setting out the revised Behaviour Category Codes appears on the next page:

Table 40: First revision of amendments of Behaviour Category Codes for Stroke Care Mapping

Note: For each behaviour category code a **T** would be used if the person was having therapy at the time of the behaviour being mapped.

Code	memory cue	general description of category
A	Articulation	Interacting with others verbally or otherwise
B	Borderline	Being socially involved, but passively
C	Cool	Being socially involved but withdrawn
D	Distress	Expressing distress
E	Expression	Engaging in an expressive or creative activity
F	Food	Eating and drinking
G	Games	Participating in a game
I	Intellectual	Using intellectual abilities
Ja active **Jp** passive	Joints	Participating in exercise with the joints while stationery
K	Kuming (coming) together	Participating in a meeting to review progress
LW -walking **LS** - standing **LWh** - in a wheelchair	Locomotion	Walking, standing, moving in a wheelchair
M	Media	Engaging in media
N	Nod, land of	Sleeping , dozing
O	Own Personal care	Engaging in activity of a personal nature such as washing, dressing, taking tablets.
P	Practical care	Receiving practical, physical or personal care
R	Religion	Participating in a religious activity
S	Senses	Direct engagement of the senses
T	Transfers	The movement of transfers from standing to sitting or vice versa
U	Unresponded to	Communicating without receiving a response
W	Work	Performing all types of work including housework
Z	Zero Option	Behaviours that fit no existing category

Table 41: Amended form used for SCM

This amended table below incorporates the forms used for mapping

Participants name:	Date:	Time Period:	Observer:
Place:			

Time													
BCC													
Goal no.													
EV													

Notes

Personal Detractions

Goals

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.

4.7 Mapping of patients using the revised SCM version

To see if the changes which have been made to SCM have resulted in improvements to the method some additional mapping was carried out. The researcher employed the help of another mapper to see if the method was user friendly and could be taught without too much difficulty to another person. It was also decided to assess inter-rater reliability of behaviour category codes between the two mappers. Six participants were mapped for one hour by two observers. It was only possible to map one of the participants who took part in the initial study which is P5; the other five participants have already been used to map goals and are P10, P11, P12, P13 and P14. The results of the maps are presented below and represent the mapping data from the most experienced mapper:

4.7.1 SCM for P10 on 19.6.98

Participants name: P10	Date: 19.6.98	Time Period: 10.00-11.00	Observer:
Place: Rehabilitation unit			

Time	11.05	11.10	11.15	11.20	11.25	11.30	11.35	11.40	11.45	11.50	11.55	12.00
BCC	TLSphy Tjaphy TAphy	TLSphy Tjaphy TAphy	TJaphy TLWphy TAphy	TJAphy TLWphy TAphy	TLWphy TAphy	Ap	Ap	Ap	Ap	Ap	Anu	Adom
Goal no.	2	2	2	2	2						3	
EV	+3	+3	+3	+3	+3	+3	+3	+3	+1	+1	+3	+1

Personal Detractions

None

Goals:

1. Mobilise with nursing staff
2. Improve mobility
3. Develop use of communication chart
4. carry over drinking liquids with head to left and chin tucked in
5. Transfer with supervision
6. Ensure safe access to bathroom
7. Maintaining continence monitor

Table 4.7.2 - SCM for P11 on 19.6.98

Participants name: P11	Date: 19.6.98	Time Period: 12.00-13.00	Observer:
Place: Dining Room			

Time	12.05	12.10	12.15	12.20	12.25	12.30	12.35	12.40	12.45	12.50	12.55	13.00	
BCC	Ap	Ap	Ap F	Ap F	Ap	Ap F	Ap F	Ap F	Ap F	F Anu	F Ap	Ap	
Goal no.													
EV	+3	+3	+3	+1	+1	+1	+1	+3	+3	+1	+3	+3	

Personal Detractions

None

Goals:

1. Stairs with supervision
2. Mobilise independently with sticks
3. Continuation of Speech and Language Assessment
4. Monitoring appropriateness of spoken output
5. To become continent
6. Wash and dress lower half independently
7. Assess problem solving skills

4.7.3 SCM for P12 on 19.6.98

Participants name: P11	Date: 19.6.98	Time Period: 15.10-16.00	Observer:
Place: By bed			

Time	15.15	15.20	15.25	15.30	15.35	15.40	15.45	15.50	15.55	16.00			
BCC	Av	Av	Av	Av	Av	Av F	Av	Av	Av	Av F			
Goal no.						3				3			
EV	+3	+3	+3	+3	+3	+3	+3	+3	+3	+3			

Personal Detractions

None

Goals:

1. Independent on stairs
2. Independent outside on slope
3. Utilise a nosy cup with free liquids (or large beaker)
4. Ensure safety (generally)
5. Improve hand and arm function
6. Improve insight into perceptual problems

4.7.4 SCM for P13 on 19.6.98

Participants name: P13	Date: 19.6.98	Time Period: 16.10-17.00	Observer:
Place: By bed			

Time	16.15	16.20	16.25	16.30	16.35	16.40	16.45	16.50	16.55	17.00
BCC	Av	Av	Av	M	M	Apsya Tipsya	TIpsya TApsya	TIpsya TApsya	TIpsya TApsya	TIpsya TApsya
Goal no.										
EV	+3	+3	+3	+3	+3	+3	+3	+3	+3	+3

<u>Personal Detractions</u>
None

<u>Goals:</u>
1. Decrease tone in legs
2. Sitting to standing (improve transfers)
3. Understanding use of thematic roles
4. Trying to encourage more fluent expressive output
5. Wash and dress lower half independently
6. Assess for return to work

4.7.5 SCM for P14 on 19.6.98

Participants name: P14	Date: 19.6.98	Time Period: 1030-1135	Observer:
Place: Samares Rehabilitation Unit			

Time	1035	1040	1045	1050	1055	1100	1105	1110	1115	1120
BCC	A TLS PHY	A TLS PHY	A TLS PHY	A TLWh PHY	A TLW h PHY	A TLW h PHY	A TLS PHY	A TLW h phy	A TLS phy	A TLWh phy
Goal no.	2,4	3,2,4	3,2,4	3,4	3,4,6	3,4,6	5,6	3,1,6	1,4,3,	3
EV	+3	+3	+3	+3	+3	+3	+3	+3	+3	+3

<u>Personal Detractions</u>
None

Goals:

1. improve transfers with one person
2. improve standing balance
3. take a sample of chest, monitoring
4. mobilise P14's arm (upper limb techniques)
5. practice sitting to standing
6. to encourage use of the McCaw
7. use of communication aid selection of correct symbols
8. word selection and copying ability
9. keep him away from free fluids (thickened fluid diet)
10. use of McCaw
11. transfer with one person properly

4.7.6 SCM for P5 on 19.6.98

Participants name: P5	Date: 19.6.98	Time Period: 14.15	Observer:
Place: Dining Room Rehabilitation unit			

Time	14.15	14.20	14.25	14.30	14.35	14.40	14.45	14.50	14.55	15.00
BCC	F Av Op	Op	Aot TLwhOT	TLWhOT TAOT TLWdOT	TLWdOT TAOT	TIOT TAOT	TI	TIOT	TI AOT	TI AOT
Goal no.				1	1	3,4	3	3	3	3
EV	+1	+1	+3	+3	+3	+3	+3	+3	+3	+3

Personal Detractions

None

Goals:

1. Mobilise with one
2. Discharge home successfully
3. Use own initiative in daily decisions
4. Encourage attention to left side
5. Ensure weekend discharge goes smoothly
6. Ensure safety in bath

4.8 Comparison of P5 between SCM 1 and the revised SCM

Comparison of P5 can be made by looking at the occupational therapy session during SCM 1 and the revised SCM method can be made. This is best illustrated if we compare a section taken from the SCM 1 data sheet with the data sheet produced above for the revised SCM method.

NAME: P5
DATE: 5.11.97

Participants name: P5	Date: 5.11.97	Time Period: 14.50-15.30	Observer:
Place: Rehabilitation Unit			

Time	14.50	14.55	15.00	15.05	15.10	15.15	15.20	15.25	15.30	15.35			
BCC	Ap	KOTA	OTa P	OTa P	OTa P	OTa P	OTa P	OTa P	OTa P	KOTA			
CV	+3	+3	+3	+3	+1	+1	+1	+3	+3	+3			

Notes:

Personal Detractions

None

There are a number of differences between the two maps worthy of note. Firstly, in SCM 1 the map does not show the detail of the OT session whereas in the revised SCM it is clear what goals are being attempted. Secondly, only the information that SCM 1 gives us is that P5 spent 35 minutes with the OT in a practice session and is not very specific about what was occurring. The revised SCM shows that P5 is engaged in an expressive therapeutic activity with assistance from an OT. Lastly, in SCM 1 a move to the occupational therapy setting would be denoted by

K, whereas with the revised edition there are details as to this move which may also incorporate a goal.

4.9 Inter-rater reliability for the revised SCM

The issue of reliability is important in the development of any tool to assess whether or not the scoring remains similar when different individuals are involved. Kitwood (1994) describes a method which he employed to assess inter-rater reliability in which he used a form of concordance coefficient. To calculate this coefficient he employed several steps. For each five minute period when two observers recorded the same Behaviour Category Code and Care Values a score of 2 was given. If they agreed on one but not both measures, a score of 1 was given. The concordance was given by dividing the agreement score by the maximum possible agreement score and it was decided to concentrate on Behaviour Category Codes. To obtain the agreement score all of the behaviour category codes were added up always taking the observer who scored the highest number of behaviour category codes for each five minutes time frame (there was never more than 3 BCC in each time frame). This provided the maximum possible agreement score. To calculate the agreement of each five minute time frame a score of 3 was assigned if all the BCC were the same and there were 3 BCC. However, if only 1 BCC was the same a score of 1 was obtained. The results of the concordance coefficients are as follows:

Table 42: Concordance coefficients

Participant	Concordance coefficient
P10	.45
P11	.68
P12	.91
P13	61
P5	.66

The concordance coefficients are only high for P12. It is likely that this occurred because the mapping of this individual was uneventful in that articulation was the only behaviour category code to be noted. However, when the individuals who were mapped began to engage in behaviours that were most related to therapy activity the reliability became lower. There are a number of possible reasons for this in examining the maps further. Firstly, there was some confusion as to whether the activity was therapeutic or not and this caused most of the difference in mapping. In hindsight this rule was not made clear to the observer. The particularly low score for P10 is found because one observer mapped down **J** and the other did not but remained mapping as **LS**. It was therefore felt that there needed to be more clarification between **J** and **L** and this would be more elaborately explained in the SCM manual. In addition, it was felt that the use of **J** (joints) active or passive was too complicated and would therefore be dropped. These changes are all noted in the final amended version of SCM.

4.10 Further Behaviour Category Code and Rule amendments

Due to the confusion on the use of **J** (joints) active or passive it was decided that the splitting of this category would be dropped and henceforth would be mapped merely as **J**. During these mapping sessions it was also noted that behaviour category code **A** (articulation) still did not assume enough importance in terms of trying to capture a person's experience of rehabilitation. Therefore, it was decided that Articulation would be mapped henceforth whenever it occurred and this would require a separate box on the SCM form. Therefore, at the end of a mapping session the amount of time spent in Articulation could be calculated along with whom the conversation occurred. There would also be a **T** assigned if the conversation was relevant to goals. It was decided that the articulation itself would not be assigned an experience value because the whole of the five minute period is an integral part of the behaviour category code and to separate the two would be a rather difficult exercise.

It was also decided to re-introduce the BCC of **X** because incontinence may be an important issue for several patients and therefore needs to be included. Table 43 which appears on the next page sets out the further revisions of Behaviour Category Codes:

Table 43: Second revision of Behaviour Category Codes for Stroke Care Mapping

Code	memory cue	description of category	age
A	Articulation	Interaction with others verbally or otherwise	14
B	Borderline	Being socially involved, but passively	
C	Cool	Being socially involved but withdrawn	
D	Distress	Expressing distress	
E	Expression	Engaging in expressive or creative activity	
F	Food	Eating and drinking	
G	Games	Participating in a game	
I	Intellectual	Using intellectual abilities	
J	Joints	Participating in active exercise with the joints while stationery	
K	Kuming (coming together)	Participating in a meeting to review progress	
LW -walking **LS** - standing **LWh** - in a wheelchair	Locomotion	Walking, standing, or moving	
M	Media	Engaging in media	
N	Nod, land of	Sleeping , dozing	
O	Own Personal care	Engaging in activity of a personal nature such as washing, dressing, taking tablets.	
P	Practical care	Receiving practical physical or personal care	
R	Religion	Participating in a religious activity	
S	Senses	Activities related to direct engagement of the senses	
T	Transfers	The movement of transfers from the standing to sitting or vice versa	
U	Unresponded to	Communicating without receiving a response	
W	Work	Performing all types of work including housework	
X	X-cretion	Episodes related to excreting	
Y	Yo-yo	Self stimulation of a repetitive nature	
Z	Zero Option	Behaviours fit no category	

In summary, the new rules for SCM are as follows:

Rule 1

The order of precedence when assigning behaviour category codes is:

1. All articulation (A) is recorded
2. Type 1 categories (E,F,G,I,J,K,L(w,s,wh),M,O,P,R,S,T,W,X)
3. Type 11 categories (BCDU)
4. N

The category of Articulation has a separate box in the stroke care mapping form, because it occurs so frequently.

Rule 2

Any Type 1 behaviour which is occurring in a therapeutic setting should be preceded by **T** for example, if a patient is being helped to walk by a Physiotherapist, it would be recorded as **TLWPhy**.

Rule 3

All behaviour category codes are denoted by the staff member involved if this is observed.

Rule 4

Any significant information lost in applying these rules should be described under notes.

4.11 Mapping of patients using the second revised SCM version

To assess this method in further detail some further mapping was carried out with one individual in a variety of contexts such as on the ward, in physiotherapy and in Occupational Therapy so that the maximum amount of Behaviour Category Codes was employed to test out the applicability of SCM. The results are as follows:

4.11.1 Individual profile for P15 on ward

Participants name: P15	Date: 16.10.98	Time Period: 1200 - 1255	Observer:
Place: By bed, alone. /Going to dining room			

Time	1200	1205	1210	1215	1220	1225	1230	1235	1240	1245	1250	1255
BCC	O	B	B	B O	O	TLW nu TLSnu	LWh nu	F	F	F	F	B
A				Anu	Anu	TAnu	Anu	Ap	Ap	Ap	Ap	Ap
Goals						4						
EV	+1	+1	+1	+1	+1	+3	+1	+1	+1	+1	+1	+1

Notes:

Personal detractions

None

Goals

1. To gain more control of movement in L /leg
2. To gain more activity in L/ upper limb
3. To become more independent on the ward (espec. A.M)
4. To improve mobility with 2 nurses on the ward
5. To use relaxation to overcome anxiety
6. Improve quality and confidence with 1 in mobility
7. Improve balance
8. OT assessment
9. Fine motor movement
10. Stretching activities

4.11.2 SCM for P15 with the OT

Participants name: P15	Date: 16.10.98	Time Period: 1300 - 1355	Observer:
Place: Rehabilitation Unit (OT cubicle) / Back to the ward			

Time	1300	1305	1310	1315	1320	1325	1330	1335	1340	1345	1350	1355
BCC	TJota	TJota	TJota	TJota	TJota	TJota	TJota Ld ota	B	B	M O	O	O
A	TAota	TAota	TAota	TAota	TAota	TAota	TAota Aota				Anu	
Goals	2	2	2 1	1 2	3	3	3					
EV	+3	+3	+3	+3	+3	+3	+3	+1	+1	+3	+3	+1

Notes:

Personal detractions

None

Goals

1. To gain more control of movement in L /leg
2. To gain more activity in L/ upper limb
3. To become more independent on the ward (espec. A.M)
4. To improve mobility with 2 nurses on the ward
5. To use relaxation to overcome anxiety
6. Improve quality and confidence with 1 in mobility
7. Improve balance
8. OT assessment
9. Fine motor movement
10. Stretching activities

4.11.3 SCM for P15 with the physiotherapist

Participants name: P15	Date: 16.10.98	Time Period: 1400 - 1455	Observer:
Place: Rehabilitation Unit			

Time	1400	1405	1410	1415	1420	1425	1430	1435	1440	1445	1450	1455
BCC	LWh pt	LWh pt	TLW pt TLW pt	TLS pt	TLS pt	TLS pt	TLS pt	TLS pt TLW pt	LWh pt	LWh pt TLW pt	TLW pt	Av
A	Apt Acpa	Apt	TApt	TApt	TApt	TApt	TApt	TApt	Apt Acpa	Tapt	TApt	Av
Goals			6 5	7	7	5 7	1	7 6		6	6	
EV	+3	+3	+3	+3	+3	+3	+3	+3	+3	+3	+3	+3

Personal detractions

None

Goals

1. To gain more control of movement in L /leg
2. To gain more activity in L/ upper limb
3. To become more independent on the ward (espec. A.M)
4. To improve mobility with 2 nurses on the ward
5. To use relaxation to overcome anxiety
6. Improve quality and confidence with 1 in mobility
7. Improve balance
8. OT assessment
9. Fine motor movement
10. Stretching activities

4.12.4 Summary of SCM for P15

Information from the three hours of SCM can be summarised in a table to provide an example of the information that can be obtained when using the revised SCM tool. The results can be presented as an individual profile below:

Table 44: Individual Profile for P15

Individual Experience Value -2.3

Main Behaviour Categories	Time/Percentage	EV
locomotion	62.5mins 35%	2.8
Socially passive	32.5mins 18%	1.2
Joints	32.5mins 18%	3.0
Own Care	25mins 14%	1.5
Eating and drinking	20mins 11%	1.0

Main Staff Member	**Time/percentage BCC**	**A**	**Goals Time/percentage Therapeutic Activity**	**A**	**EV Mean**
pt	55 30%	50 28%	45 25%	45 25%	3.0
ota	35 19%	35 19%	35 19%	35 19%	3.0
nu	10 5%	25 14%	5 3%	5 3%	2.0
cpa		5 3%			
subtotal	100 55%	115 64%	85 47%	85 47%	
Other					
p		25 14%			
v		5 3%			
subtotal		30 17%			
Total	100 55%	145 81%	85 47%	85 47%	

From the above three data sheets it can be seen that by using the second revised SCM tool a lot of information is now gained about the behaviour that the patient is engaged in and whether that behaviour is of a therapeutic nature or not. We can see how much conversation is occurring and whether it is of a social or therapeutic nature. We can look at who the interactions are with in terms of time to see who the patient spends the vast majority of their day. We can quantify goals and see how much of the person's day is spent in working towards those goals set in rehabilitation. Information can be obtained about whether the goals that have been set by the multi-disciplinary team are transferred to the ward environment. We can see from looking at the maps what goals were worked towards with which professional and this illustrates that for example, a nurse and an occupational therapist were observed carrying out a movement goal 1. We can also obtain information on the value of the experience for the person. It is felt that the picture gained of the patient's day is now much more detailed, and with this mapping tool, a patient's day to day experience can be more adequately assessed.

4.12 Last Amendment to rules

The final amendments to the rules can be divided into three parts:

1. During the mapping of articulation it was noted that when the **A** was put into the box this did not specify the time spent talking and a generalisation was being made about duration of conversation. In addition, it was decided that mapping articulation was possibly making the SCM tool over complicated to use, particularly when analysing a number of individuals. In addition, it was difficult to see how much more valuable the information was using this category separately. It was therefore, concluded that it would be best to revert to the old

method of including articulation within the other behaviour category codes.

2. It has been found while mapping that therapeutic activity always revolved around a goal and therefore it was felt unnecessary to prefix each BCC with a T, as this information was already obtained when mapping goals and staff involvement. In connection with this point it was also noted that coding for the different individuals involved with the person being mapped was not utilised fully in SCM 1 and 2, as the style of mapping revolved around the professional not the BCC. This meant that in the analysis staff involvement per se was not so relevant. However, with the change in BCC's to centre around the behaviour occurring, making note of staff/other involvement becomes increasingly important. For example, it can of itself be used to plot the amount of time a person spends in occupational therapy for example. In terms of the development of the manual it was decided that 'interaction with others' should always be noted and methods were developed to analyse these results in the SCM manual. In addition, in order to rationalise the potential range of staff and for ease of mapping it was decided that a demarcation would not be made for example between occupational therapy assistant's and occupational therapists. This would ease the task of the mapper as on occasions it can be hard to distinguish the exact rank of which professional involved. To ease the task of the mapping further it was decided to simplify the professional codes which are outlined in the manual.

3. Experience of this last mapping suggested that it rather complicated to map each behaviour that occurred over the five minute period and it became difficult to summarise time frames. Therefore, it was decided

to re-instigate a similar procedure than the one which had been adopted hitherto.

The latest version of the technique, along with instructions on carrying out the analyses is outlined in the SCM manual included as Appendix 2.

CHAPTER 5

5.0 Discussion

This aim of this research has been to develop and assess the applicability of Dementia Care Mapping to stroke care. Stroke Care Mapping has potential as a tool that attempts to provide an understanding of the process of rehabilitation for stroke patients from their perspective. SCM was conducted with 8 participants during the course of a typical day from 9.00am to 4.00pm. Discourse analysis was used to provide further information on the process of rehabilitation. The results were used to devise a training programme for staff following which SCM was carried out again on 6 of the original participants observed (unfortunately, 2 participants had been discharged in the intervening period. Comparison of the 'before' and 'after' results show that SCM can be used as an observational tool and provides information which can be used as a basis for the training and education of staff, which attempts to place a greater emphasis on person-centred care in the rehabilitation environment.

5.1 Hypothesis 1: DCM can be applied with some alteration to the area of stroke rehabilitation

Dementia Care Mapping has been extensively used to measure the quality of care in a hospital ward or residential setting for someone who has dementia. To decide if DCM can be applied to the area of stroke it is necessary to ascertain whether stroke care mapping can capture the unique components of a person's experience on a rehabilitation ward. This was attempted in SCM 1 and SCM 2 following a number of changes to the original Dementia

Care Mapping format to incorporate therapy and staff involvement. However, experience of using this tool pointed to the value of further changes, one of which was to map goals in the rehabilitation environment a fundamental difference between the input of stroke and dementia patients. The evolution of the SCM method has already been outlined and demonstrates that SCM is a tool which can be adapted for use in stroke rehabilitation. The SCM manual illustrates the method in simple terms and provides a rehabilitation ward staff with all the information they need to carry out mapping sessions.

5.2 Hypothesis 2: SCM can be used to examine the quality of care and the experience of the stroke patient whilst in rehabilitation, which will involve including the input provided by therapists.

There are many reasons why SCM is a useful tool to examine the experience and quality of the stroke patient whilst in rehabilitation:

1) SCM provides a snap shot of a person's experience in terms of how they spend their day. This may be carried out to provide information on how patients spend their time or it may be useful to have some detailed information on a particular individual for a variety of reasons; for example, a patient may have been on the unit for a long time and because they have almost become a 'fixture and fitting' of the ward their rehabilitation has lost momentum. A need for an individual approach could also apply to a patient who has obtained a label of being 'difficult' on the ward. SCM can try to understand their experience more objectively by careful independent observation rather than through the rumours and hearsay of staff members. The results of the mapping can be utilised in structuring further rehabilitation

for a person or trying to understand the nature of a person's experience to help overcome challenges or difficulties that can arise.

2) Several patients can be mapped and the results can be aggregated to provide relevant information for the whole unit. The variety of permutations with SCM is enormous and can be adapted to the requirements of the rehabilitation unit. SCM can be used to obtain a review of what the experience of rehabilitation is like for several individuals. This can be done to look at the quality of the service or gain further insight into the ward environment. SCM can also be used to examine certain times of day or study a variety of contexts such as lunch hours or time spent in the therapy unit. This flexibility of approach means that SCM is not a rigid tool but one that can adapt and change according to the requirements of the ward. It is also possible to use only part of the SCM tool; for example, goal setting may not be well developed on the rehabilitation ward, so that part of the SCM tool need not be analysed and instead the focus can be on Behaviour Category Codes and Experience Values. Conversely, it may be that staff wish to focus exclusively on goal setting on the ward and the transfer of goals outside of the therapy setting. The tool enables staff and management to look in a much more objective way at what is occurring and where improvements could be made for an individual patient or for the ward as a whole. SCM can also be employed to evaluate the effectiveness of a training programme by carrying out mapping before and after the training sessions. It may also be used to assess the impact of any changes that have been made to the Unit and to see if these changes affect the patients' experience.

3)To assess whether SCM can measure quality and experience it is useful to compare this tool with other methods which have been used to examine activity levels and how patients spend their day while on a rehabilitation ward. With regard to activity levels the results of SCM 1 illustrated that the levels of engagement for stroke patients on the rehabilitation ward were low. This low level of activity has been noted in previous research, which found that patients spend large amounts of time inactive and simply staring into space (Tinson 1989, Waters 1992). One study of some 63 patients in a stroke rehabilitation ward estimated that passive behaviour occurred some 42% of the time (Keith and Cowell 1987). If we take the same definition of 'passive' as the previous researchers to mean that of sitting, lying or sleeping and watching television the figure of 43% can be obtained for SCM 1. This illustrates an almost identical amount of time spent in a passive form of behaviour within these two studies. A similar percentage was also found by Kennedy et al (1988) who found that some 44.5% of the therapeutic day from 9.00a.m. to 5.00pm was spent in the ward area in 'isolated disengagement' or 'non-specific gazing'. This finding appears to be replicated time and again and can also be illustrated by Gamlen et al (1989) who found that between 8.30pm to 4.30pm patients on a stroke unit spent 35.8% of their time in disengaged or inactive individual tasks.

4) Comparisons can also be made between the results of SCM 1 and 2 and findings from other rehabilitation wards as to the amount of time spent in therapy. In SCM 1 the amount of therapy received per day was averaged at 42 minutes and this increased in SCM 2 to 56 minutes per day. The figures for SCM 1 are similar to those already found in previous research. One study attempted to estimate the amount of therapy given to inpatients by multiplying the presumed average length of sessions (30 minutes) by the number of sessions received in the first 6 months post stroke (Wade et al. 1984). According to this retrospective study acute inpatients spent on average 45 minutes per day in therapy (occupational therapy and

physiotherapy combined) during their hospital stay. This represents only 3.4% of the patient's waking day. Several years later, Tinson (1989) found that stroke patients spent a little more time in therapeutic activity and the average figure had increased to 12.9% of an average day which amounted to some 62 minutes of therapy (53 minutes spent in occupational and physiotherapy). However, the amount of time does vary in that Keith and Cowell (1987) found that patients spent nearly one third of their time in treatment, although this study was conducted in America and it must be remembered that rehabilitation methods may fluctuate from country to country. Even though these figures can provide a useful benchmark they should be used with caution because this research shows that the amount of therapy time does not remain static and can vary from day to day. For example, P8 had 35 minutes of occupational therapy during SCM 1 and this compared with 10 minutes during SCM 2 and P7 had 15 minutes of physiotherapy during SCM 1 and 45 minutes during SCM 2. Fluctuations will occur for a whole variety of reasons. It has been proposed that therapy may vary according to age in that older patients appeared to receive more therapy (Tinson 1989). However, the present research did not find this to be the case and there was no evidence that the amount of therapy depended on the age of the patient. It was, however, noted that the amount of therapy varied according to the physical abilities of the individual patient; for example, P1 did not have any therapy at all during SCM 1 when she was still relatively weak physically but received 20 minutes during SCM 2. The results also reveal that patients received more therapy (occupational therapy and physiotherapy) during SCM 2, which suggests that as individuals progress through rehabilitation the amount of therapy increases, and it is also interesting to note that a large proportion of those patients where an increase in therapy was recorded had transferred to the 'more able' side of the ward.

5) Although, the results of SCM 1 and 2 show that the level of activity and therapy time can be measured with this tool and compared with other research, it could be argued that SCM is able to provide a great deal of additional information about a person's experiences and therefore is a much more valuable tool when compared to the previous research which looks at how patients spend their day. For example, Keith and Cowell (1987) state that their research observations are gross because there was no classification of treatment modality within disciplines nor was there any judgement about the quality of care. They classify watching TV or reading a magazine 'passive' behaviour, however, if this behaviour is a positive experience and the person is very engrossed in what they are doing, rather than merely flicking through the newspaper because there is nothing else to do, it seems unfair to classify this as 'passive' behaviour because this implies that the person is not an active participant. The advantage of SCM is that it not only examines behaviour category codes but also assigns experience values, and so goes some way towards examining the quality of each type of experience for the person. So this method not only attempts to look at how a person spend their day in rehabilitation but also about what levels of well-being/ill being a person experiences during the course of their day.

6) Goals are such a central feature of stroke rehabilitation that the assessment of the amount of work towards them and the degree of achievement of them should become increasingly important as a measure of quality, both in terms of how they are set, and how often they are carried out. Incorporated into the overall SCM tool is a technique for mapping goals in the rehabilitation environment. Previous research has demonstrated a lack of goal-directed rehabilitative care (Gibbon and Little 1995). A similar finding has also been made in this research which illustrates that goals are only practised when the relevant member of the multi-disciplinary

team has a session to work on those goals, and that they are not extended into the general rehabilitation environment which is largely operated by the nursing profession. This may occur for a number of reasons. Firstly, the nurse is often geographically separated from the therapy areas which can often lead to an interruption in the continuity of rehabilitation and communication problems inevitably occur (Cox 1973). Secondly, the lack of understanding of the nurses' role and lack of clarity as to what therapists are attempting to achieve may also explain why the nurses may be reluctant or hesitant about carrying out what they may class as physiotherapy goals. Young (in press) has recently carried out some interesting research in this area in trying to enhance nurses knowledge of physiotherapy with the hope of breaking down these barriers to established practise. Inter-professional programmes have previously been found to help reduce barriers and create greater understanding and communication with an additional benefit of increasing moral and positive attitudes towards patients (Skeil 1995).

It is vital that there is some follow through of goals into the general rehabilitation environment in addition to the therapy sessions. This is not a new idea; some fifty years ago Barker and Wright (1951) stated that physiotherapy should be carried over into the overall rehabilitation environment because of the close fitting relationship between humans, objects and actions, which they described as the 'behaviour-milieu synomorphy'. They demonstrated that certain behaviour is demanded by certain settings, which may explain that whilst a patient may walk well in the therapy room they revert to a limp on the ward. If goals are not global across the modality of the therapy room to the ward then the nurses may not know what to expect or encourage. Staff can often be surprised by the lack of carry over from one therapy session to another in terms of goals and when this is actively demonstrated through SCM staff can work together to address this problem. This demonstrates the use of SCM to improve the quality of this aspect of rehabilitation.

7) With its emphasis on personhood DCM attempts to get at the very heart of the malignant social psychology which often pervades care settings and this emphasis can be used in SCM. The identification of and awareness of the possible effect of personal detractions can help staff to affect the experience of individuals during their rehabilitation in ways it is hoped will maintain a person's well being. The personal detractions component of SCM can be very beneficial in demonstrating to staff who, in the vast majority of cases, are often not aware of the impact of what they say to patients and do not stop to consider what effect this may have on the individual. However, it is important to note that the collection of information on personal detraction coding is subjective and therefore can be subject to bias. One of the potential difficulties in this area revolve around the use of humour and during the training sessions some staff stated that some comments are aimed at making everyone laugh. On these occasions the mapper has to decide whether this was made at the person's expense or not. Despite these difficulties in interpretation, it is important to remember that the whole point of the coding is to try and help staff to step inside the patient's shoes and develop empathy. The experience values themselves also try and measure the value of an activity or interaction for a person and this can be used in part to assess the quality and value of a person's day.

8) SCM focuses on the quality of care by examining the very process of care. To date much of stroke research into quality has concentrated on outcomes which tend to be focussed on the physical aspects of patient orientated outcomes and have been less concerned with the process and the experience of the patient. They have tended to focus on individual functions

as ‘apparatus errors’ and not on the person as a complex whole (Lewinter and Mikkelsen 1995) Some recent research has attempted to apply practise guidelines to bridge the gap between the process of care and outcome (Forbes et al 1997). Quality criteria have been established which are as follows: appropriateness of client for rehabilitation, baseline assessment, rehabilitation goals, treatment plan, prevention of complications, secondary stroke prevention, monitoring client’s progress, managing functional health patterns, involving the client and family in the rehabilitation process, educating client and family and the discharge process. The establishment of such criteria are admirable but they do not examine the detail of the process of rehabilitation which is measured by SCM and they do not take account of the importance of the rehabilitation environment as such. Again this shows how outcome measures have tended to be directed at specific aspects of organ function when the ultimate effects of rehabilitation are better captured in terms of overall function across the domains which involve items such as social interaction (Kane 1997). An outcome in rehabilitation is invariably measured using the following formula:

Outcome = (baseline, risk factors, treatment, environment)

In this analysis the environment does not often involve the social environment of the individual in rehabilitation. However, it could be argued that one of the ultimate aims of rehabilitation is to secure social well being for rehabilitees (Pomeroy 1997). This is appropriate for the short and long term and SCM goes some way towards trying to ascertain this aspect of well-being in terms of experience values for stroke patients. Indeed, SCM could be seen as the window to one aspect of the rehabilitation environment, which has tended to be subsumed by an emphasis on maximising independence rather than one which also focuses on well-being. The idea being that if well-being is maintained rehabilitation is likely to be maximised. This is a very important area to consider because although, on the one hand, the environment of the stroke patient may provide protection, safety, and care but the patient may still lack stimulation, challenge and opportunities to learn. One outcome of a poor environment may be a mental deterioration that is unrelated to pre-stroke condition or age but instead due to inactivity, depression and disuse of mental faculties (Walsh 1976). There is also a tendency to attribute behaviour more to changes in the person's personality, attention span and lack of motivation following a stroke than to the environment (Carr et al 1987).

9) SCM does not ask the person on the rehabilitation ward about their experience of care and assessment of its quality and this could be one of the major criticisms against the SCM method. It is vital to consult individuals on levels of satisfaction with the services they have received and whether they would recommend any particular changes. However, there are a number of reasons why it is still relevant to use a tool to measure a person's experience. Firstly, as mentioned earlier, stroke can often lead to cognitive impairment which can have varying effects depending on the site of the lesion, and this may affect how a person is able to report their experience; for example, a person who is unable to communicate or who has significant memory difficulties may be a poor reporter of their experience. Secondly, many older people tend to be grateful for whatever service they receive and these lower expectations can sometimes filter through as a result of older people's perception of themselves, often fostered by ageism in our society and lead to artificially high results. Lastly, it is important to distinguish between satisfaction and experience. Experience tries to capture what is occurring rather than a person's perception of that experience which may depend on their mood or cognitive ability whereas satisfaction is based on what the person feels is the most important aspect of their rehabilitation. For example, Pandora (1994) asked patients what they thought was the

most important aspect of their rehabilitation and the results overwhelming supported the value and increased use of physiotherapy even though this approach has still to prove its efficacy. Although we could assume that if someone has a positive experience they would score highly on satisfaction and it is known that satisfaction does correlate with outcomes of care (Fowler 1995). Lastly, it is important for staff to measure a patient's experience because the very process of stepping inside someone's shoes for a period of time may be one of the most important ways of nurturing empathy.

10) SCM is not mutually exclusive and could be used in conjunction with some of the other quality indicators that are evolving which evaluate the ward environment. Although it may be argued that rehabilitation should be reducing the number of measures, each component has a fundamental part to play. It is also argued that SCM is one of those important components in that it helps all of those working in rehabilitation not to forget the individual perspective, and it is from this platform that certain other changes may evolve such as the introduction of a care pathway which is based on the person rather than on the profession. There is a place for an individual perspective in that rehabilitation is not a single, discrete entity. This has led some researchers to argue that it is foolish to talk about the outcomes of rehabilitation. Rehabilitation is a treatment applied to a given clinical problem. Thus, one must address the rehabilitation of 'X'. There is no room for an overall endorsement of the product. Effectiveness of rehabilitation for one condition says little about the effect on another (Kane 1997). There is room for a measure such as SCM because rehabilitation consists of many parts of which the environment is a crucial component. However, because of these many parts assessing its outcomes is much more complicated than assessing the

outcomes of a surgical procedure (Kane 1997).

5.3 Hypothesis 3: a training intervention will have a positive effect on the results of SCM for individual participants

The effects of the training intervention can be divided into two separate areas. Firstly, it is possible to compare the same patients before and after the training sessions using SCM tools, such as the frequency and duration of behaviour category codes, care values and the number of personal detractions noted. Secondly, if any particular changes have occurred in the ward environment SCM could be employed to see if this has brought about a change for the patients.

5.4 The comparison of behaviour category codes and care values

In comparing mean care values of participants between SCM 1 and SCM 2 only a small positive difference was found for five out of the six participants following the training sessions. There could be a number of reasons for this, in that, the care values themselves may not be sufficiently sensitive to subtle changes in the provision of care. In the likert scale of care values there are only 6 options to capture the experience for an individual; whilst this makes for good inter-rater reliability, it perhaps lacks something in terms of sensitivity. At first glance, it may appear that the mean care values are skewed by the different amount of times spent in therapy sessions between SCM 1 and SCM 2 for a number of patients; for example, it can be noted that for P3 the amount of OT reduced from 90 minutes to 20 minutes between map 1 and map 2 and because a one to one interaction generally scores in the range of +3 the reduction in therapy could result in a diminution in the overall care value which is a function of time spent rather than quality of care. However, when therapy was taken out of mapping altogether the care values remained roughly similar. We can also see that the care values increased for each hourly breakdown between mapping sessions, and this was particularly noticeable between the hours of 0900-1000 where the care value rose from 1.6 to 2.6.

The most striking result from SCM 1 to SCM 2 was the elimination of personal detractions following training. Results from the personal detractions that occurred during SCM 1 show that the majority are in the mild range and the most common of which is talking about a person in his/her presence. However, there are also some severe detractions such as mistreating a person as an object and using threats. However, the elimination of these personal detractions following training is a very encouraging result and could indicate that the training and personhood video may help to encourage empathy between staff and patients. As soon as a patient on the ward is not seen as ‘them’ by the nurses (who may have regarded themselves as ‘us’, a distinctly different group) then respect may develop which shows itself in the way a person is treated and the elimination of personal detractions may illustrate this finding. However, it may also mean that because staff have developed an awareness of what the mapping is recording second time around they modified their comments or speech accordingly. Another possible explanation is that personal detractions may have disappeared of their own accord during the second mapping and this change was not a direct result of the training. However, if this were the case it would represent a very marked drop from 35 personal detractions noted during to SCM 1 to none during SCM 2.

The change in behaviour category codes between the two maps also indicates that following training behaviours such as I (intellectual) and E(expression) were being mapped which had previously been observed. The reduction of the amount of time in B (socially involved but passively) may have occurred as a result of the training. It is worth noting that in the training intervention staff expressed some surprise that patients spent so long doing nothing in the morning and it appears that they have acted on this finding because the results show that the amount of time spent in B (socially involved but passively) reduced most markedly between the hours of 0900-1000 hrs when this category reduced from patients spending about one third of their time in this passive state to less than 10% of this hour.

There was also a notable increase in the A (articulation) category from SCM 1 to SCM 2 for the nursing profession, which means that staff were talking more to patients without performing another task at the same time. This conclusion can be drawn because in the rules of SCM, A (articulation) is coded as a Type 11 category (which can only be mapped when a Type 1 category is not taking place). This finding suggests that during SCM 2 interaction with patients did not only occur during the execution of other tasks, which has been commonly found in the nursing literature (Nichols 1993). In addition, the quality of interaction noted by the difference in care values between SCM 1 and SCM 2 for the A (articulation) behaviour category code showed a small positive change. This finding may have occurred because the training has enhanced not only the amount of dialogue between staff and patients but also the quality of conversations and this difference is most notable for the nursing profession. However, it is equally possible to state that the difference in articulation occurred because the participants were getting to know each other more and they may have been feeling better and so felt more likely talking.

5.5 Changes to the rehabilitation ward as a result of SCM

Following the training intervention staff recommended a number of changes which took place on Samares ward, this suggests that one of the positive benefits of SCM is that it encourages staff to consider and attempt to adapt the care environment. The introduction of these changes are encouraging because they mean that staff have acted on the training in a positive way and this serves to confirm a finding by Burton (1980) that feedback alone can be sufficient for behavioural change. However, research from behavioural mapping on a spinal injury unit where staff planned to increase patient time in the therapy department was not demonstrated in the second study which revealed little change (Kennedy et al 1988). It may be suggested that these changes came about simply because some training was carried out on the ward but their relevance to the quality of a person's day does suggest that staff have been thinking directly about the implications of the SCM results. The changes which were implemented on Samares ward are listed below:

1) There was a decision to implement additional groups in the morning time to try to decrease the amount of time that patients spent in the behaviour category code of B (socially involved but passively). The nature of the groups is presently under discussion.

2) It was thought that it would be important to employ an extra staff member for .5 week specifically to look at activities and leisure time for patients.

3) The formation of a discussion group which included the multi-disciplinary team, in which staff wanted to look more critically at the service provided. This group was sparked of by the results of the SCM and led to consideration of many other areas outside of the specific remit of the

mapping method. In this discussion group there is presently an examination of the utility of adopting a care pathways approach to documentation for the stroke rehabilitation ward. The concept of care pathways has increased in popularity of late (Edmans et al 1997) and within this pathway a large section has been devoted to the results of assessment. On Samares ward it was decided not to divide the assessment by disciplines, but to look at the various facets that make up a person and use these as the categories; for example, rather than having a section for physiotherapy the assessment has a category on mobility. This illustrates that staff are beginning to think of the person foremost rather than their own specific therapy disciplines.

4) Following on from the development of goals in the SCM method, feedback was provided to staff on the results obtained, from which two points emerged: firstly, staff became aware that the goals which had been set for patients were often vague and therefore not directly observable, and secondly they were surprised at the lack of goal carryover into the general rehabilitation environment. It was decided that there would be a training session on goals and a handout was away from having goals denoted by a professional group but rather to describe them in terms of which aspects of the person need rehabilitation.

5.6 Hypothesis 4: Discourse analysis will be helpful in examining the process of rehabilitation in terms of interactions with staff and patients

The taped conversations (which have been transcribed and analysed) provide a whole wealth of information on the nature of spoken interactions between staff and patients on the rehabilitation ward with some interesting results.

5.7 Discourse analysis in the ward setting

The results of discourse analysis in the transcripts of the ward show that during these times participants spend a great deal of time in silence and share little of the conversational floor. Nurses ask the majority of questions and these are almost without exception related to aspects of care. There is little conversation and the introduction of topics outside of nursing is rare. This result confirms a view held by Blytheway (1995) who states that outside of the immediate context of the service being delivered the lives of the recipients are irrelevant. He states that in the provision of nursing services what the nurse has to offer is no more (and no less) than what nursing has to offer, and in the course of a typical day the nurse may provide nursing care to several recipients but the several are no more (and no less) than the recipient several times over. Similarly, one particular recipient may receive care from several nurses, one succeeding another because of illness, holidays, resignations, promotion and so on, but again the service provided to the recipient remains unchanged: it is being provided by a nurse to a recipient, with the emphasis on the service, 'the what', rather than on the people, 'the who'.

The transcripts taken during SCM 1 reveal that the nurses perform tasks which will make sure the person has been fed and watered but that there is little other conversation as shown by the low use of topics introduced into the ward setting. Results indicate that the patient is largely in receipt of yes/no and forced questions on the ward which illustrate the encouraged role of passivity of the patients. This supports the findings of Tfouni et al. (1991) who examined the 'mechanics' of conversation and found there to be an asymmetry in the interaction, which qualifies the nurse-patient interaction as 'one of control, domination and effacement of individuality'. Henry

(1965) provides a vivid description of a hospital setting many years ago, which has some similarities with treatment of patients seen in this research:

> *"The staff, though animated by solicitude and kindliness, seem to maintain an attitude of indulgent superiority to the patients, whom they consider disorientated children, in need of care, but whose confusion is to be brushed off, while their bodily needs are assiduously looked after. Tower is orientated toward body and not towards mind. The mind of the patients gets in the way of the real business of the institution, which is medical care, feeding, and asepsis. Anything rational that the patient wants is given him as quickly as possible in the brisk exchange of duty, and harsh words are rare. At the same time the staff seems to have minimal understanding of the mental characteristics of an aged person. As for the patients, they live out their last days in long stretches of anxiety and silent reminiscing, punctuated by outbursts of petulance at one another, by TV viewing, and by visits from relatives. There is no inner peace, and the social life is minimal."*

There is so much in this passage with which some of the transcripts of the present research have a certain resonance, to suggest that little seems to have changed from the early 1960's to the late 1990's. Patients are in many contexts, treated as children with the overuse of kindly but inappropriate words, intonation involving high and variable pitch ("baby talk" (Caporeal, 1981)), and frequent use of directives. This can be seen as a realisation of the myth of old age being a "second childhood". There are also long silences which are present in the tapes and conversations which serve to illustrate the preoccupation of the nurse with the body and not the mind. The stereotypes of a childlike state identified with an older adult who has a physical disability may explain some of the power differentials noted in the conversations between nurses and patients. This can be shown by the greater use of commands, interruptions without apology, the 'them' and 'us' atmosphere, the use of critical comments, and speaking about patients as if they are not there. In addition, the length of utterances between nurses and patients were shorter than for any other taped conversations, which suggests that the nurses may have been using a simpler syntactic structure with patients. A similar result has been found by Rubin and Brown (1975) who noted that students used significantly shorter utterances to explain the rules of a game to older adults (who they assessed to have lower intellectual abilities than young adults). The use of intonation is also of significance which has been documented as baby talk (BT) by Caporael et al (1983).

The results of limited nurse-patient interaction have been replicated before (Lipman et al 1979, Wells 1980, Syred 1981, Godlove et al 1981, Macfadyen 1984, Lanceley 1985, Pennington and Pierce 1985, Armstrong-Ester and Browne 1986, Seers 1986, Clarke and Bowling 1989, Armstrong-Ester et al 1994). Research has also found that what limited interactions do occur are predominantly staff initiated, treatment orientated and of short duration. The language used is often of a 'controlling' nature, thereby inhibiting patient response. It is important to try and explain why it is that nurses and patients have such limited interaction. It is possible that the nurses perceive they do not have time to talk about other matters when carrying out tasks such as breakfast orders, requests in the dining room or medical procedures. However, the transcripts do show that, particularly during breakfast when the patient is at their bedside, there is time to talk but that nurses prefer to talk to each other, and this is shown is demonstrated by the background conversations of the transcripts.

The limited social interaction which has been observed may also be explained by the 'social model of disability' in that the attitudes and actions of other people actively disempower those who have some kind of 'difference' overlooking their attempts at action and denying them a voice (Makin 1995). Because stroke patients are perceived as disabled within that model, they are therefore treated differently. This can be shown in part by the different background conversations which occurred between nurses while engaging in nursing tasks, in which, they tended to ask each other more open ended questions and introduced more topics of conversation than when talking to patients. Conversations between the nurses were found to contain many statements which are very different from conversations with patients which have as their emphasis 'yes/no responses. This emphasis has been found by Ashburn and Gordon (1981) who noted that speech between care-givers and volunteers to patients involved more questions and repetitions than were recorded when talking amongst their peers. The overuse of the yes/no category of questions indicates that the patient is constrained in terms of their communicative choices. Coupland et al (1988) stated that constrained communicative choices resulted from negative stereotypes of ageing. This is further confirmed by the 'them' and 'us' observations presented in the results which have been previously found by Kitwood (1990) in his research which elaborated further the malignant social psychology so often found in care environments, and which revealed that in the field of dementia patients are by and large stereotyped as a group and not taken as individuals. The consequence of this is that they are depersonalised linguistically and no attempt is made to find out about patients as individuals on a personal level. Stereotyping can be observed in the results section as to what constitutes an 'old' person; for example by the speech noted under the heading 'ignoring cues'. One example of this is where the nurse assumed the apparent lack of understanding by the patient was due to a hearing difficulty. Such attitudes may occur because there is a tendency to make many assumptions about a person who has had a stroke with the resultant physical disability. This concept of 'overgeneralisation' was found by Coupland et al (1986) who noted that simplified talk to the visually handicapped was employed, thus overgeneralising from a particular sensory handicap to encompass the level of understanding as well.

Lastly, nurses may also be responding to their whole culture of training which is so wrapped up in the medical model, which encourages nurses to cut off from the real feelings of their patients and this can be achieved by the use of distancing tactics (Maguire 1985, 1989). These distancing tactics are conversational ploys which block a patient from expressing their true feelings or worries, and can include jollying patients along, selective attention to narrow, physical aspects of a patient's condition and obstructing attempts at reassurance. This has been observed in one study of nurses' interactions with elderly residents in a long stay environment in which the nurses deflected and played down some of the seriously expressed concerns, thoughts and feelings of older people (Grainger 1990). This can be referred to as under-accomodation (Giles et al. 1993). Under-accomodation or the use of distancing tactics may well have occurred in this research; so it would serve to explain the overuse of closed questions and a preoccupation with tasks. Examples of this type of interaction have been noted in the results section under 'unresponded to'. This preoccupation with a task orientated style of nursing was examined by Menzies (1970) who looked at predictable aspects of nursing organisation and behaviour. He refers to 'ritualistic task performance' whereby the attention of the nurses was directed to the performance of tasks rather than to the patients as individuals. He also noted the depersonalisation of nurse and patient was encouraged in training which emphasised the interchangeability of nurses to patients because their approach was standardised and regimented. This approach educates the nurse that his or her role is as a provider of functional services, services which can be provided by any other nurse. This in turn encourages nurses to use the sort of depersonalising phrases which have been noted in the transcripts such as ‘the dysphagics’. By referring to a person in this way one of the essential ingredients of distinctiveness which is essential to maintain a sense of self (Breakwell 1986) is missing. When a person is being referred to as ‘a dysphagic’, this vital sense of distinctiveness is undermined, and this in turn disrupts a continuing sense of self-definition with a potential consequent effect on morale and motivation. In the present research it is interesting to note that a taped interaction between a patient and member of staff which was highlighted in the results section for particular attention was one where the staff member was not a nurse but a domestic who has therefore not been trained in the medical model. This example serves to support the process of medicalisation which serves to influence nurses functional treatment of the patient and drawing them away from the patient as a person. Because the whole orientation of nurse training has traditionally revolved around tasks it may be that the nurse would feel guilty if she were to have a conversation with a patient, as if she is not concentrating on her job. This raises the whole issue of whether nurses view talking as ‘real work’ (Jarrett and Payne 1995) and it may be that unless the nurses are carrying out tasks they do not feel as if they are really working; such feelings will only arise because of the perception that having a conversation with a patient is not part of her job.

5.8 Discourse analysis in the therapy sessions

The transcripts of the therapy sessions were different from the ward based settings in that, generally speaking, these sessions are carried out with a professional on a one to one basis for a specific purpose and therefore the nature of the interaction will be very different. In therapy sessions a greater deal of participation is expected and therefore one would expect the patient to have a greater share of the conversational floor and a lower level of silence. However, some aspects of the interaction are worthy of note; for example, the therapists appeared to be making greater use of open questions which encourage the patient to participate and the types of sentences vary. There was also a greater use of statements by therapists which is a positive indication in a therapy session and moves it away from an interrogation or question and response mode of operation. In addition, the therapists introduced topics outside of the therapy into the conversation and so did the patient. However, the amount of minimal responses was roughly equivalent to that on the ward which is surprising given the increased amount of open questions. It may be that in the ward the patient is encouraged to be a passive participant and therefore this spills over into the therapy sessions or it may relate to the conversational style of the patients. The one therapy session which stands above the others distinguishes itself by the amount of sharing of information. In this session the OT shares information about herself with the patient and this creates and encourages conversation and mutual participation, although both participants are still able to focus on the task in hand. This emphasis on discourse was researched by Coudry (1993) a Speech and Language Therapist who examined language pathology orientated towards discourse. She found that by introducing a diary and photograph album the speaker had an opportunity of being the main speaker and to influence the dialogic direction. She found this had an advantage because it allows for a reversibility of roles. This helps to move the patient away from being the passive participant and into being an active force in their own rehabilitation. There are some similarities with this exchange and the interaction between the patient and the OT which stands out from the rest, in that, the OT was using the patient's own make up to practise its application and this may have helped the patient to be more active in the therapy session. This puts rehabilitation in the context of what the patient has done before and thereby creates a sense of meaning to what is occurring.

When comparing interactions of therapists and nurses it may be proposed that the results have not compared like with like, in that, we have compared one to one therapy sessions with the ward based interactions between nurses and patients. To overcome this potential criticism the results section analysed three transcripts between patients and different members of the multi-disciplinary team. A similar pattern of results was obtained in that nurses did not initiate topics, tended to have a greater share of the conversational floor, make less use of statements and a larger proportion of silence was also noted. Of course, we have not considered the individual dynamics of the patients but it is interesting that a very similar pattern of results should emerge. Therefore, it may be proposed that nurse have a similar pattern of responding whether on a one to one or in the ward setting

5.9 Recommendations to improve the quality of interactions

From the discourse analysis there are a number of recommendations that can be made with regard to improving the quality of interactions on the ward:

1) The environment could be adapted to encourage more conversation particularly between patients. In the ward situation each patient spends a large proportion of time sat next to their bed. They are separated from each other which means that it is hard to converse easily with the person in the next bed, particularly if they are not mobile and hard of hearing. It would be helpful if patients were asked if they would like to be seated together. In the dining room the patients are not organised in a social group and the seating around the table is reserved for mealtimes, therefore it does not encourage conversation. There is also often a TV on just prior to lunch which some patients are able to see and this also minimises interaction. It can often be observed that while some people are watching TV others are not interested and are trying to converse with another patient over the noise of the TV. To improve this situation it is proposed that the layout is changed and that seating is arranged differently. It may also be helpful if the TV were moved to a separate location that could be designated as a TV room. Much of the conversation around mealtimes revolves around repeatedly asking questions about meal selection. It may be better to have a menu located clearly in the dining area so that people can make his or her own selection. This makes it more natural and encourages the person to have a sense of control, so that they know what is on the menu and they can have time to make their selection. This may also encourage a topic in conversation that revolves around the menu.

2) It is proposed that one reason for the failure to develop meaningful interactions between nurse and patient may revolve around the uncertainty of the role of the nurse in stroke rehabilitation which is reflected in the literature (Gibbon 1993, O'Connor 1993). It may be that this lack of role leads nurses to develop an over emphasis on tasks as the nurses' 'role'. It has been observed that all too often the nurses contribution is viewed as the

provider of 'maintenance care', whilst the therapy goes on around her (Gibbon 1993). This is certainly reflected in the current research which shows that there is little carry over of goals into the general rehabilitation environment. This 'maintenance care' role needs to be challenged and a specific role for nursing in stroke rehabilitation needs to be developed, along with permission for nurses to carry out this role. A review of the literature indicated that the role most clearly associated with nurses in stroke rehabilitation is that of providing a context conducive for rehabilitation (Kirkevold 1997). In addition, nurses being present at the ward 24 hours a day are charged with creating a 'positive atmosphere' that facilitates patient's possibilities of benefiting from the therapeutic interventions (Indredavik et al 1991). The nurses' continued presence on the ward is assumed to facilitate development of a supportive relationship between the nurse and patient, but it is not clarified what specifically these activities encompass or how they contribute to the patient's recovery. Nurses are also frequently considered an 'understudy' to other therapists, supporting and taking over their functions when they are not available. There is often a specific therapeutic dimension implicit in the nurses role, but the actual functions associated with it remain elusive (Kirkevold 1997). To uncover the specific therapeutic role of nursing in stroke care Kirkevold (1989, 1992) studied the actual care provided by experienced nurses on a specialised stroke unit. Four therapeutic nursing functions were uncovered: interpretative, consoling, conserving and integrative. The conserving functions revolve around preventing complications and trauma and the meeting of essential needs. In relation to the consoling and interpretative function, which means helping patients and relatives understand the ramifications of the stroke and the provision of emotional support, very few studies specifically focused on how nursing care should be designed to improve the patient's psychological functioning and well being. Therefore clear guidelines about duties connected with psychological care need to be delivered and backed up by the management on the ward to support the importance of this work. Permission is needed so that the nurse is not and does not fear being chastised by the manager or a colleague for talking to a patient rather than performing a task.

3) The results of the discourse analysis also raise questions about how, when and where to deliver training. Concern about the quality of nurse-patient communication has led to considerable work on nurses' communication skills. There is a large literature that emphasises the importance of communication in caring for patients (Sundeem 1989) and aims to improve communications skills of nurses and other health professionals (Porritt 1984, Kagan 1985, Dickson et al 1989, Faulkner 1993.). The process of communication skills training for nurses has also been described with some positive outcomes (Tomilson et al 1984, Crute et al.1989 Lloyd 1991). Communication skills training has become an established part of basic and post basic nursing and physician education (Fallowfied 1993). It is important to consider why it is that even though there is now some emphasis on the importance of relationships in nurse training, the findings of discourse analysis on the rehabilitation unit do not suggest that there is a follow through from what is taught. One reason for this may be that, no matter what training is offered, once a nurse enters a hospital environment the culture of the medical model is all pervasive and even the best of intentions fall in with the established culture of 'them' and 'us'. Those who trained before communication skills were introduced will be the senior nursing staff on the ward, or in management. Their position and influence may neutralises the effect of training as they will have things done their way. Perhaps the focus of training has been short sighted and should be attempting to capture process rather than the rather more sterile classroom sessions about

psychology. Attempting to provide nurses with information about the experience of the patient via techniques such as SCM or the feeding back of the results of discourse analysis along with a specific training intervention based on the ward's results may prove to be one of the most powerful tools against the all pervasive presence of the medical model which fuels negative attitudes towards patients. Recommendations for future training include targeting an intervention around discourse analysis along with recommendations to nurses about what constitutes an interaction which involves both partners. From listening to and examining the various conversations, a number of statements can be made with regard to what constitutes a spontaneous, easy-flowing interaction that fully engages both conversational partners:

- when questions are used to seek information from the other conversational partner, these are most frequently in the form of wh-questions, giving the least restriction on the answer from the conversational partner
- a low proportion of directives are given, reflecting no power differentials between speakers.
- the share of the conversational floor is roughly equal, showing that both partners are equally contributing and giving full turns.
- the time spent out of conversation (i.e. silence) is a low proportion of the whole transcript.
- a number of different topics, outside of care, are introduced by both speakers.

Although this represents an ideal and there will be times when this type of conversation is inappropriate it will provide an indication about some of the ingredients of an 'ideal' interaction. Nurses could be shown that in the majority of transcripts this type of conversation does not occur. It could be argued that this is because of poor conversational abilities of the older adults, but research has shown that the basic conversational skills of the normally ageing elderly are usually well preserved (Shadden 1997). However, some cognisance has to be made of the speech problems that are prevalent following stroke and responses could and should be tailored appropriately, perhaps with the help of the Speech and Language Therapist. It is important to point out that in the present research only P7 had language difficulties. Nevertheless, for this person the quality of conversation still changed depending upon who was the conversational partner, which demonstrates that the differences in quality of the conversations were not as a result of the abilities of the patient. This also demonstrates that, even for those with language difficulties, the quality of conversation could still be high depending on the conversational partners. Two particular conversations have been picked out for special attention in the results section as examples of the spontaneous easy flowing interaction: that of a conversation between P3 and an Occupational Therapist and a conversation between P5 and a domestic. However, there were no differences between wh-questions and yes/no questions. This may have occurred because there were very few questions asked anyway as the majority of the conversations comprised a large number of statements.

Another approach which appears to have some promise in attempting to change the nature of interaction between nursing staff and patients has been proposed by Salmon (1993) who found that a higher proportion of interactions were positive during formal activity periods than at other times. These results did not depend on whether or not the nurses had a positive attitudes as measured by a questionnaire. He therefore recommends that formal activity periods are encouraged in ward settings where a high level of appropriate interaction is encouraged, and argues that this would give nurses the necessary permission to interact with patients at a social level and not to feel guilty that they should instead be involved with physical care.

5.10 Hypothesis 5: Discourse analysis will be a useful additional component of SCM

Although SCM provides a great deal of useful information on the rehabilitation ward, it cannot capture the richness of detail provided by a technique such as discourse analysis and it therefore offers a complement to some of the reductionist techniques that are employed in SCM. However, the one drawback is that the process of transcribing the tapes and analysing the material is very time consuming and with this in mind it may be unlikely that this type of technique would be used routinely as a method of collecting information on the ward. In addition, some methodological problems were apparent in this current research which would need to be considered if discourse analysis were to be employed with the SCM method, but lack of time and resources prevented changes being made and a re-evaluation carried out.

Improvements could be made in the taping of conversations; for example, it would have been helpful if a recording could be made for each participant in a set number of contexts, which themselves also need to be more specific. This could involve the breakfast time period and a specific therapy session such as dressing practice. However, at breakfast time it cannot be guaranteed that the patient being taped will speak a great deal or become involved in a conversation. The dining room itself was very useful for providing information about the environment of the ward, but again participants' conversations were limited. Another possibility would have been to have a voice activated tape recorder which the participant carries around all day and then each and every conversation is picked up. However, given the time it takes to transcribe conversations this may not have been a very practical solution and the length of periods of silence would not be recorded. In addition, this would not have shown where the silences occurred which do provide valuable information. Possible improvements in the methodology would include putting the tape on for longer periods and perhaps start tapeing one week before to mitigate against observer effects (Milroy 1991).

Criticism has been made of discourse analysis by suggesting that there is a lack of attention to the sequential nature of conversations. It is also said to rely on subjective notions of what is correct and not correct and a premature formalisation of patterns of conversation. In the present research, hypotheses were based only on previous research, which meant that the hypotheses of what we expected to find were well founded. In our analysis we also paid attention to the sequential nature of conversations, as can be seen in the section on 'repair'. In addition, in our analysis of types of clause, although we categorised and quantified types of clauses, it was felt that this still provided valuable information in examining the complex dynamics of power differentials between patient and professional. It is recognised that in doing this analysis, information about the functions of each clause was simplified as single sentences can be used to form two or more speech acts, for example, a question can also be an offer and we were only looking at a number of discourse functions. Despite these critcisisms, Lupton (1992) has defended discourse as " a valuable way of understanding the underlying assumptions in health professionals communication with their clients". Levinson (1983) has suggested that 'there may be some room for some kind of accomodation or even synthesis between the two positions, and it was with this in mind that this study has elements of both types of analysis; indeed, the present research tried to overcome these criticisms by analysing the data using not only specific analysis but also trying to identify themes such as 'unresponded to' amongst many others, while also listening to consider the sequential nature of the conversation.

Despite the time-consuming nature of discourse analysis, the qualitative method itself is an important tool in the study of the nature of professional interaction. By subscribing to a model of the scientist as one which corrects the clinician's subjective biases by systematic checking and evaluation through precise quantitative research, the practical experience in applied roles which provide the insights about the complexity of human responses and of interaction can be lost (Davison and Lazarus 1994). Therefore this kind of analysis has a place, and so much could potentially be gained by this method being increasingly employed: indeed, Henwood and McQueen (1998) have found that qualitative research is increasingly being published and funded.

Although discourse analysis has much to offer, it is important to point out a number of methodological improvements that could be made if this were to be carried out on another occasion. Firstly, it would be essential to tape all conversations during the course of the day whilst carrying out SCM, otherwise it could be argued that the texts that were transposed have merely been used because they supported a particular viewpoint. However, to incorporate discourse analysis as a routine feature in SCM sessions may prove too difficult. SCM itself is a complex process and it is unlikely that staff would have the time to map and then transpose tapes. Future recommendations could try and simplify the method of analysing conversations to include the use of a checklist. This checklist is relatively simple to use and gives a rough indication of the quality of the conversation. This is much quicker than the painstaking process of taping conversations and transcribing the contents. The information obtained from this checklist could also be used to look at the type of questions, the share of the floor, the amount of silence and the number of topics which itself provides much information on the dynamics of a conversation. Inevitably, some information is lost as against full discourse analysis but it could be suggested that a checklist is much more workable and user friendly than the traditional method of transcription. A checklist could point out the important features of a conversation so as to indicate what could be changed and improved upon in terms of staff training. This measure could also be repeatedly used to evaluate changes in discourse. The checklist could be as shown on Table 45:

Table 45: Proposed checklist

Conversational Partner CP		Partner P	
Greeting			
Questions	yes/no		
	Alternative		
	Wh-		
Statements			
Directives			
Total Turns by CP			
Topic initiation			

Extra Comments:
Interruptions
Unrepaired
Silence (secs)

The potential use of this checklist has yet to be piloted as a possible adjunct to SCM.

CHAPTER 6

6.0 Conclusions

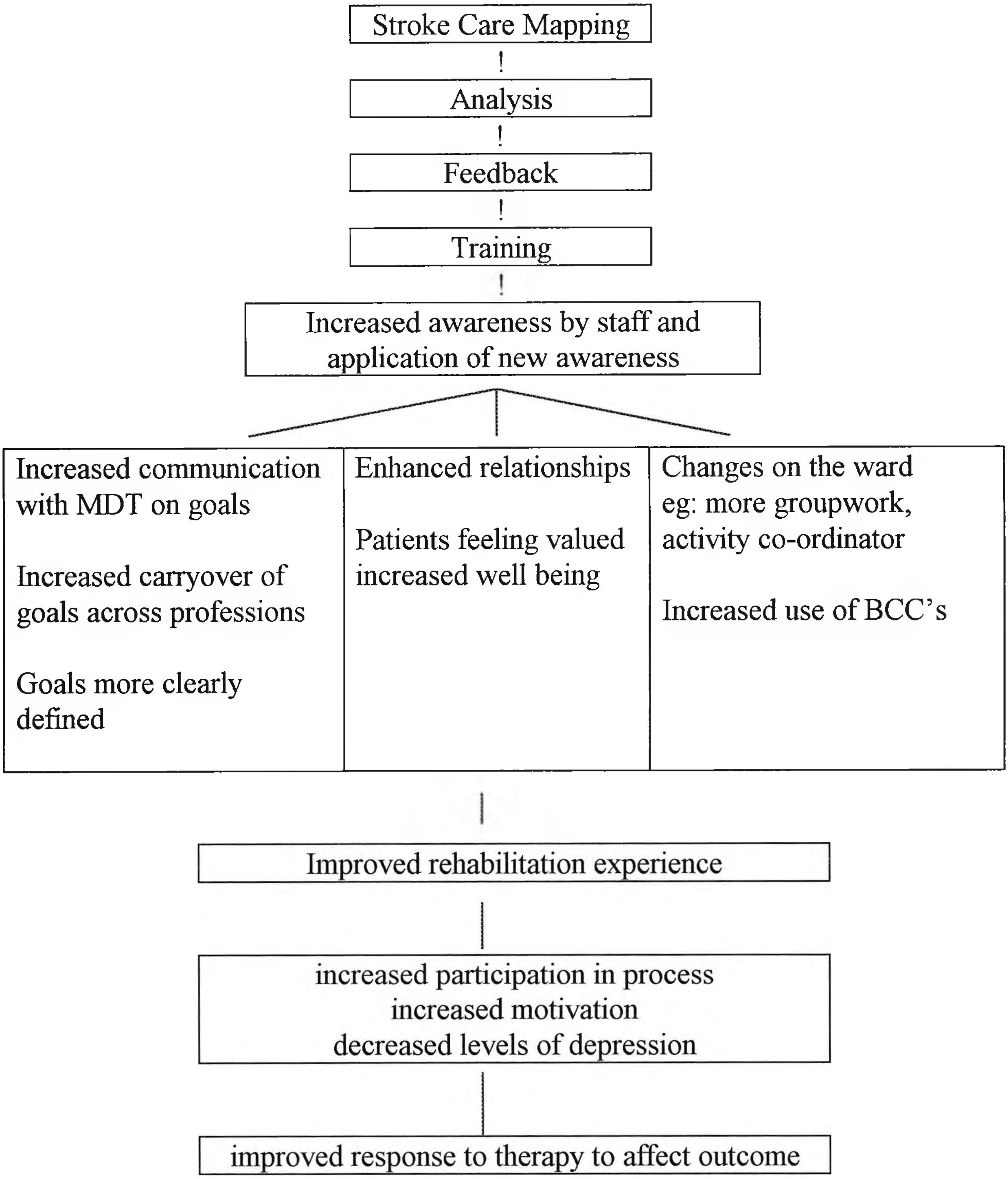
This research has shown that DCM can be adapted to the area of stroke rehabilitation and that this approach has some potential. Care has been taken to point out the differences between the areas of stroke and dementia care, the most obvious of which is the treatment regime as individuals who have had a stroke generally receive rehabilitation towards some degree of recovery whereas dementia care is largely custodial in nature as there is no such recovery objective. However, the one factor which appears to unite the two areas of dementia and stroke is the culture of care which is prevalent in the ward environment, which accords with previous findings that many rehabilitation wards often provide little more than routine geriatric care (Baker 1978, Fairhurst 1981Waters 1994). The traditional culture of dementia care has at its base the medical profession as the ultimate source of knowledge, and the priorities for understanding revolve around having a clear and accurate understanding of a person's impairments with an emphasis on cognitive functioning (Kitwood 1997). In this traditional culture, caring is limited to giving physical care in a competent way and making sure that the person's basic needs are met, but psychological needs are not prioritised and minimal interaction between a patient and ward staff is the order of the day. Many aspects of this culture are as prevalent in the area of stroke care (at least, outside of therapy), which remains entrenched in accepted forms of practice (Waters 1994), with a common set of negative beliefs towards stroke patients (Gibbon 1970, Wild 1994), with a well-defined organisational structure and an established pattern of power. The DCM method attempts to bring about fundamental cultural change by seeking to minimise the “us/them” barriers by embracing the concept of ‘personhood’. Adapting and applying this approach to stroke rehabilitation will put the same fundamental cultural change very clearly on the agenda and represent a move away from the medical model of care so often seen in this area.

Education is often the first step in bringing about change and continued education and training programmes for staff have been hailed as the distinctive features of successful stroke rehabilitation (Stroke Unit Trialists Collaboration 1997). The results of SCM can be shared with staff in the form of a training programme to provide an insight into the experience of care as viewed by the patient. The present research has attempted to show some potential in providing a framework for the process of change. It has been noted that after the training programme and subsequent SCM 2 an increase in the amount and quality of verbal interaction between nursing staff and patients was found which showed that patients were having more conversations with staff members outside of everyday nursing tasks. Secondly, the elimination of personal detractions during SCM 2 may suggest that staff have obtained an increased awareness of the impact of a malignant social psychology and are now thinking about what they are saying to patients. This change has the potential to enhance well-being for patients on the ward. In addition, the role-playing sessions within the training programme, where staff played the part of a patient receiving personal detractions, seemed to have a significant effect in conveying the vital message of the importance of the patient as a person and may have helped to encourage the development of empathy. Prior to the training sessions many staff simply did not realise that they were using personal detractions, which suggests that they were non-deliberate but habitual, and it is suggested that this arises from the traditional culture on rehabilitation wards with its emphasis on functional achievement rather than on personhood. Many were also surprised that patients were left in a passive state for such a substantial part of the day, a realisation which led to tangible changes on the ward, such as the development of increased group work and the introduction of a part-time nurse to focus on activities and leisure time. Such positive developments are likely to improve the experience for patients still further.

Following training care values also increased which demonstrates a small but positive effect in terms of a person's experience in rehabilitation. It may be possible that one of the benefits of increasing well-being for individuals undergoing rehabilitation will be to maximise what he/she can achieve and thereby affect outcome. This may be achieved by providing a person with a feeling of being valued and supported which may lower feelings of depression or anxiety and could lead to increased levels of motivation. The flow chart presented on the next page may serve to illustrate the process by which the process may enhance well-being and maximise an individual's outcome in rehabilitation terms. The propositions in this flow chart will need further empirical analysis, but it has already been proposed that process measures have a potential to be used as proxy measures of outcome (Stojcevic et al 1996).

Flow chart shown as Figure 11 to illustrate the process of change for individuals in a rehabilitation ward which carries out SCM:

Figure 11: Process of rehabilitation for stroke patients



This flow chart shows how increased awareness can potentially bring about changes in goal activity. In this chart an increased feeling of well-being along with possible changes on the ward have the potential to have a positive influence on a person's experience during rehabilitation. These changes may influence outcome, which is the fundamental objective of rehabilitation. It may be that there is a causal link between the two aspects, the proposition being that if a person feels increasingly valued this is likely to promote a sense of well-being which as a consequence may make a person more likely to respond well to the rehabilitation effort. This is only a proposition and considerable research would be required to validate it; however it accords with the model of motivation drawn from the work of McDaniel (1976).

The whole process of SCM has brought about some changes on the ward, and in particular the nature of the training sessions with their emphasis on the person may help to break down the traditional culture of care in rehabilitation. However, the degree to which these effects are lasting is of crucial importance. Previous research has shown that although nursing staff made plans to increase activity levels in a spinal cord injury unit after feedback from an observational study on low levels of engagement, little had changed a few months later (Kennedy et al 1988). This indicates that feedback alone is not enough to affect change and illustrates how difficult it is to initiate institutional change. Whilst it is very likely that a short burst of training, as utilised in this research, may well begin the process of changing long-established ways of interacting with patients, it is felt likely that the pervasive cultural backdrop may well easily come into dominance within a short period on the basis "old habits die hard". It is therefore crucial to ensure that personhood training is ongoing and that SCM is carried out regularly as an integral part of ward activity so that the new approach becomes even more of a habit than the previous one. To ensure the follow-through of SCM, a number of staff on the ward could be invited to train in SCM with a regular flow of feedback to staff in ward meetings. Such an approach would not only keep other staff very aware of the patient's experience, but would also ensure that the nurses who are mapping continue to nurture a sense of empathy by attempting to step inside the shoes of a patient and their world in the ward environment. Indeed, continued training has already been found to enhance staff morale and motivation (Stroke Unit Trialists' Collaboration 1997). Once SCM is well established on the ward it is anticipated that staff may feel an increased sense of satisfaction, the benefit of enhanced meaningful relationships. However, this will only be successful if the management on the ward embrace cultural change and give staff permission, indeed encouragement, to change their emphasis and value them for the contribution which they make, for nurses will not make the necessary changes if they fear criticism for doing so. It has already been noted that there is a close connection between the personhood of patients and that of the staff (Kitwood 1997).

Although the results of this study suggest a small positive effect as a result of using SCM and the subsequent training it cannot be assumed that all these changes occurred as a result of the training intervention. It may be that the changes were seen because during the period of 8 weeks between SCM 1 and SCM 2 patients may have been feeling better in themselves. The knock on benefit of this may have resulted in them doing and talking more. The elimination in personal detractions may have also simply disappeared anyway without any intervention. Future research should try and control for these variables. It may therefore be possible to carry out the research again with a shorter period of training for staff before reassessing using SCM. However, training of this intensity can be difficult to organise on a ward with many members of staff and limited time available.

In terms of the development of the SCM tool it will need to embrace some of the components deemed necessary for an ideal stroke outcome measure, namely: validity, reliability, sensitivity to clinically relevant changes, simplicity of administration and communicability to non-specialists (Wade 1986). With regard to the question of validity (of whether SCM measures what we intend it to measure) further exploration is required and to do this it would be useful for a patient to map experience values at the same time as the mapper to see if there was a concordance in their results. Reliability is a broad concept that has many different meanings, but the most important aspect for the SCM tool is that of inter-rater reliability, which assesses whether or not the scoring remains similar when different individuals are involved. Some attempt was made to test this with SCM but given the final refinements of this tool more needs to be done in this area. This tool is sensitive in that it was able to map clinically relevant changes from SCM 1 to SCM 2. Its utility as a "before and after" measure can be demonstrated, although it is questionable as to whether the care values are sensitive enough to pick up subtle changes in behaviour as a results of an intervention such as staff training. With regard to whether SCM is simple to administer we only have the experience of DCM as a benchmark. Staff would need to be trained in SCM as they are for DCM, which involves a two day course in administration and interpretation. DCM has found that it can be successfully taught to all forms of staff from the level of managers to domestics. SCM does however have a number of differences from DCM and, although one person has been trained in the tool without difficulty, more systematic training needs to be carried out to ensure that the tool is easy to use. In the development of any instrument the issue of acceptability is also of crucial importance (Hunt et al. 1986). During the time that patients have been mapped we have sought their permission and have received no refusals or complaints. Generally speaking, it seemed that patients often forget that the mapper is there after a period of time.

Further work on the SCM tool is also needed to focus on gaining some comparative work in other stroke environments. It would be useful to see how useful this tool is viewed by other staff members. It may be argued that it is time consuming, but in order to achieve quality information it is necessary to take the time, and if cultural change is the ultimate result then its value is enormous. If more stroke units are interested in trying SCM then it may be possible to obtain norms of what levels of experience values indicate quality services, and indeed it may be useful to have benchmarks for what levels of therapy are appropriate for different levels of disability, although this may vary too much according to the individual characteristics of the person.

The results of the discourse analysis were very helpful in setting the scene for SCM to take place and in illustrating the culture of care that was prevalent. Because each participant was not taped for the whole of the day, the results of the discourse analysis are tentative. However, from the tapes that were analysed verbal interactions between nurse and patient were often characterised by an asymmetrical interaction. This means that nurses did not tend to initiate topics, had a greater share of the conversational floor and employed the use of questions and commands much more than statements. The nature of these interactions implies a power differential that is likely to have an effect on the nature of interaction between nurses and patients. The results suggest that the role of the nurse is task orientated as there was little social exchange, which only serves to reinforce the passive role of the patient in the traditional culture of care and reduce the patient's sense of individuality. However, the interactions with therapists were not so asymmetrical and there was less of a power differential between patient and professional. Discourse analysis provided an insight into the ward and certain recommendations could be made in light of the results. These suggestions revolved around making some changes in the environment, implementing formal activity periods, and staff training to address attitudes and interpersonal communication. Some of the recommendations were similar to those proposed in SCM and the staff training that took place was also aimed at tackling communication. It can be concluded that discourse analysis does provide a wealth of information and complements SCM. However, as previously noted, it is very time consuming, too much so to be likely to be used on a regular basis. It is therefore important that the SCM tool is able to achieve its objectives on its own without discourse analysis, although some form of checklist to record certain matters could be a useful optional adjunct to SCM; this is an area in which further research is required. In developing any tool the fundamental requirement, as pointed out by Wade (1986), is that one always has to consider the ease with which an instrument can be administered and taught because this will determine its use. It is therefore vital to make SCM a simple, user-friendly and effective tool. A tool which attempts to focus on the experience of the person in stroke rehabilitation as a means of maximising individual potential, rather than seeing the rehabilitation of a stroke patient solely as a mechanical process which works on a damaged body to obtain optimum functioning.

CHAPTER 7

7.0 References

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