UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

School of Psychology

The Assessment of Post-stroke Shoulder Pain

by

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ABSTRACT
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About 20,000 U.K. stroke patients a year experience pain in their affected shoulder during the course of their recovery. Its causes are unclear and widely debated. It has been suggested that more effective assessment of it would clarify the problem. However, assessing pain in stroke patients is complex because many have perceptual, cognitive and language problems, making existing instruments unsuitable. Pain assessment can be seen as a process of social interaction by which information about the experience of pain, in the form of verbal report or non-verbal signs, is encoded, detected and interpreted by another person. Thus the aim of this thesis was to investigate stroke patients' experiences of shoulder pain and the way communication about it occurs in hospital settings in order to inform better ways of assessing it.

Mixed methods were used to investigate post-stroke shoulder pain from three complementary standpoints. Stroke patients' experiences of shoulder pain and its communication were explored through focus groups and analysed using interpretative phenomenological analysis. The detection of shoulder pain behaviours in patients with communication deficits was investigated through critical incident interviews with health professionals. To assist patients who are unable to use existing pain measures, a pictorial scale of pain intensity was developed and evaluated.

Findings from these small studies revealed that stroke patients perceive shoulder pain to be affected by a range of physical, psychological and contextual factors. They believe many hospital staff lack awareness of it, that structured pain assessments are hardly ever used and that everyday communication about it is rare. Health professionals vary in their responsiveness to patients' shoulder pain. Some show expertise in discerning behaviours that indicate it and use detailed reasoning to verify their assumptions, whereas others show less sensitivity. Some patients with language deficits can convey information about pain with help from staff; others may be able to learn how to use tools that are designed to capitalize on their strengths. It was concluded that the psychological and contextual factors that influence pain should be considered in greater depth, that better education of staff would raise awareness of pain and the regular use of assessment instruments targeted to the specific needs of patients would improve care.

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List of Abbreviations

CAS	Coloured Analogue Scale
CSAG	Clinical Standards Advisory Group
FACS	Facial Action Coding System
FAS	Facial Affective Scale
FPS	Faces Pain Scale
FLP	Functional Limitations Profile
HADS	Hospital Anxiety and Depression Scale
HMT	Hodkinson Mental Test
IASP	International Association for the Study of Pain
ICP	Integrated Care Pathway
IPA	Interpretative Phenomenological Analysis
NHP	Nottingham Health Profile
NRS	Numeric rating scale
RAI	Ritchie Articular Index
RRU	Regional Rehabilitation Unit
RSD	Reflex Sympathetic Dystrophy
SPIN	Scale of Pain Intensity
SROMP	Shoulder Range of Movement to Pain
TENS	Transcutaneous Electrical Nerve Stimulation
VAS	Visual Analogue Scale
VRS	Verbal Rating Scale

One of the staff nurse, she pulled my arm like this and I said, ‘Please don’t there’s such a pain round there.’ She said, ‘Strokes don’t have any pain.’ I could not believe that. I mean I know I’ve got the pain, why would I make it up? Because the pain is restricting me from so many things. She said, she said, ‘Stroke patient don’t have any pain.’

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Chapter 1
Background

1.1 Introduction

The development of shoulder pain is a common and distressing occurrence for many stroke patients. It is also a problem that has been perplexing health professionals for decades. Despite widespread research into this condition, there are still significant gaps in our understanding of it and consequently, management of post-stroke shoulder pain in health care settings leaves much to be desired. Why is this the case?

There are various explanations, which will be discussed in more detail in the following two chapters. But in brief, stroke patients are a heterogeneous population and selected groups have often been studied, making generalisation impossible. Some investigations are limited by methodological weakness and in others, findings are contradictory. Thus the body of evidence to support associations between pain and its probable causative factors is inconclusive (Price, 2004). It is generally assumed that physical deficits are most likely to give rise to pain, but the influence of psychological factors has hardly been investigated at all. Several studies conclude that the causes of post-stroke shoulder pain are multi-factorial (Bender & McKenna, 2001; Turner-Stokes & Jackson, 2002; Van Langenberghe, Partridge, Edwards, & Mee, 1988), but the relative significance of different variables is unclear.

A further confounding factor suggested by some is the inconsistent and sometimes inappropriate choice of assessments used in research to evaluate pain in stroke patients (Price, 2002; Van Langenberghe et al. 1988; Wanklyn, 1994). Whereas clearly accepted practices exist for formal assessment of shoulder pain in the general population (Crawford Adams & Hamblen, 1995), there is no such consensus for stroke. This is partly because signs of shoulder pathology are harder to determine in patients with deficits of neurological origin, such as upper limb paralysis, but also because the giving and receiving of information about shoulder pain from stroke patients is complex.

Firstly, pain is a subjective multi-dimensional experience that is difficult for any individual to explain to another. It is more so for stroke patients whose appreciation of pain may be affected by sensory and perceptual deficits. Secondly, though pain is bestrated by self-report, the questionnaires and pain rating scales used in the non-stroke population may be inappropriate for stroke patients with visual deficits or limitations of language and understanding (Price, Curless, & Rodgers, 1999). Thirdly, because being in hospital is distressing, it can be difficult to distinguish between behaviours arising from pain as opposed to other states, such as confusion or anxiety.

From a clinical perspective, the possibility of shoulder pain should be routinely considered by doctors, nurses and therapists, so that appropriate care can be offered if it develops. However, pain in general may be poorly communicated, assessed and documented in health care settings (Blomqvist & Hallberg, 1999; de Rond, de Wit, van Dam, Muller, 2000) and this has been cited as a specific problem in stroke patients (The Intercollegiate Working Party for Stroke, 2000). It is even more likely if they have communication problems and are cared for by health professionals without the specialised knowledge and experience needed to recognise signs of pain in the context of these problems (Kumlien & Axelsson, 2000; Sloman, Ahern, Wright, & Brown, 2001). This may result in inadequate treatment (Kehayia et al., 1997), which increases the risk of developing a long-standing pain problem.

1.2 Earlier development work

Personal involvement in an audit project to improve the management of shoulder pain in stroke patients prompted the work presented here. This began in May, 1999 at a Regional Rehabilitation Unit (RRU) which admits patients aged 16-65 with complex neurological conditions for multi-disciplinary rehabilitation. A number have shoulder pain on arrival and others develop it during their stay. An earlier first round retrospective audit of case notes had revealed that only two out of 104 patients had a record of their shoulder pain problem from onset to resolution. Documentation was poor and there was no clear system for management. This finding led to the development of a multi-disciplinary integrated care pathway (ICP) to prompt timely delivery of care, co-ordinate intervention, educate staff and to enable audit of both process and outcome (Jackson et al., 2002). To inform the pathway, a review of the medical literature was undertaken (Turner-Stokes & Jackson, 2002).

It was recognised early on that assessing shoulder pain would play a fundamental part in guiding the care pathway and in judging its efficacy, but no instruments suitable for this purpose were identified from the literature. To begin with a simple questionnaire, the ShoulderQ (Turner-Stokes & Rusconi, 2003), offering patients a choice of verbal or visual analogue pain scales, was devised to make it as easy as possible for patients to report on the aspects of shoulder pain that clinicians perceive to be relevant for management decisions. Although some were able to use the ShoulderQ to describe their pain and its severity in different circumstances, about a third could not, and a need for enhanced ways of enabling this group to self-report was identified.

For patients unable to self-report, clinicians had to rely on what they were able to discern from simple language or gestures, supplemented by observations of pain behaviour and reports from other people. This information recorded as comments in case notes formed the only record of pain status and was sparse. Moreover, how it had been arrived at was unclear. Although the interpretation of signs of pain by another person may be subject to bias, some suggest that this could be reduced through the development of a more systematic procedure for evaluating pain behaviour in stroke patients with shoulder pain (Pomeroy et al., 2000). Thus a further identified need was to explore the 'unspoken language' of shoulder pain behaviour in order to inform a more effective assessment procedure for patients with communication deficits.

1.3 Summary

Researchers have highlighted the importance of developing better ways of assessing post-stroke shoulder pain and this has been supported by recent clinical experience. But do we know enough about what we need to assess and why? There are good reasons for asking these questions and for doing some preliminary work before better instruments can be designed. Little has been documented about stroke patients' experiences of shoulder pain, how they convey its presence to health professionals and how these staff detect and document it. Investigating these issues will make an original contribution to our understanding of post-stroke shoulder pain and will be an essential first step on the path to improving assessment, management, and hence patient care. It is the main objective of this thesis.

Chapter 2

Shoulder pain after stroke

2.1 Chapter outline

The aim of this chapter is to examine current knowledge of shoulder pain after stroke through an appraisal of the published literature. It begins with a brief overview of the background, presentation and problems of people who have had a stroke and then focuses on the occurrence and postulated causes of shoulder pain. Factors that have been poorly researched are given greater emphasis than those that have been discussed widely in published literature reviews.

The reasons for needing to assess pain are then presented, followed by an analysis of the shoulder pain measures used in research studies to date. It is argued that there is little consistency in these measures and that a number are inadequate for their purpose.

In contrast to this account of objective forms of assessment, the way some clinicians classify shoulder pain syndromes is discussed. The chapter ends by touching on the problem from the patient's viewpoint as told in some subjective accounts of post-stroke shoulder pain. It is concluded that the biomedical literature has been too narrow in its focus and that to adequately understand the nature of post-stroke shoulder pain, we must first find out more about patients' experiences of it.

2.2 An overview of stroke

The annual incidence of stroke in the U.K. is estimated to be 100,000 (Kelson, Ford, & Rigge, 1999), accounting for 5% of all acute medical admissions and about 4% of the National Health Service budget (Rudd et al., 1999). About 30% will die and 40% will be left with a residual disability (Langton Hewer, 1994). The prevalence of stroke survivors in a typical district of 250,000 has been put at 1,500; 50% having significant disability (Wade, 1997).

World Health Organisation criteria define stroke as: 'Rapidly developed clinical signs of focal disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than vascular origin.' (WHO, 1989). The underlying vascular disorders causing stroke can broadly be divided into infarction, responsible for80-85% of cases and haemorrhage, responsible for 15-20% (Lindsay, Bone, & Callander, 1991).

2.2.1 The spectrum of impairments

The clinical features of a stroke range from minor to catastrophic depending on the vascular region affected, the spread of cerebral damage and whether the dominant or non-dominant hemisphere is involved. It is well established that immediately following a stroke, there is likely to be paralysis of the side of the body contra-lateral to the cerebral lesion (hemiplegia), which is characterised by hypotonia (reduced muscle tone) in most patients (Teasell, 1991). This tends to evolve into a state of hypertonia (increased muscle tone) over a period ranging from 24 hours to a year or more (Ryerson & Levit, 1991; Van Ouwenaller, Laplace, & Chantraine, 1986). Either state may co-exist with sensory loss, muscle weakness and loss of normal range of motion. The consequence is a temporary or permanent loss of function. Patients admitted to hospital with a stroke are a diverse group because they vary in terms of their stroke severity, the extent and nature of their impairments and the course of their recovery.

Among the many problems facing stroke patients, loss of arm function is particularly distressing. It is a common occurrence; 24% of survivors still have moderate or severe upper limb paralysis three months after onset (Parker, Wade, & Langton Hewer, 1986). In the longer term, a large UK survey found that up to 45% of stroke survivors over the age of 55 reported difficulty with activities requiring upper limb function, such as getting dressed (Tennant et al., 1997). In contrast, a smaller prospective study found that 67% of a group who had undergone in-patient rehabilitation experienced non-use or disuse as a major long-term problem four years later (Broeks, Lankhorst, Rumping, & Prevo, 1999). This higher figure may reflect a selected group with more severe strokes and/or the fact that more sensitive tests of arm function were used.

Loss of arm function has a profound impact on daily life. The shoulder is the most mobile joint in the human body, enabling placement of the arm and hand for a range of activities. The arms are essential for everyday functional tasks, such as dressing and eating, and integral to social activities, such as sport or dance. Furthermore, they play a crucial, if more subtle, part in maintaining the posture of the body and have a communicative function in expressing ideas and moods through gesture. All these abilities are at best restricted and at worst completely lost when paralysis is severe.

As well as losing function in a physical sense, survivors frequently have deficits of communication, cognition and vision. For example, aphasia[1] affects about 15% (Wade, 1997) and over a third may have visuospatial neglect[2] (Halligan, Marshall, & Wade, 1989). Also common are homonymous visual field deficits such as hemianopia[3] (Patel & Taylor, 1999). Thus patients with a non-functioning upper limb often have a complex blend of additional problems to contend with.

2.2.2 Concurrent health problems

There is a high prevalence of co-morbid disease among survivors of stroke. Coronary artery disease occurs in 32% to 65% and about 40% have diabetes (Black-Schaffer, Kirsteins, & Harvey, 1999). Both conditions are associated with hypertension, add a further dimension of ill health to patients and prolong recovery time (Cull & Will, 1991). Furthermore, since a high proportion of patients are elderly, they are prone to general frailty and to disorders associated with ageing, for example arthritis, which can affect the shoulders (Langton Hewer, 1994).

Stroke patients are liable to develop secondary complications, which largely arise from their enforced immobility and precarious physical and psychological condition (Sackley & Dewey, 2001). For example, the shoulder is vulnerable to injury from falls, which are common in patients with neglect, confusion and balance deficits (Davenport, Dennis, Wellwood, & Warlow, 1996; Langhorne et al., 2000). Depression is a common consequence (Robinson, Bolduc, & Price, 1987) which often goes undiagnosed (Black-Schaffer et al., 1999) and which may both exacerbate and be exacerbated by pain.

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[1] Aphasia is the inability to express thought in words, or an inability to understand thought expressed in the spoken or written words of others and is most likely to be a consequence of left hemisphere strokes.

[2] Visuospatial neglect, also known as unilateral visual neglect or hemineglect, is a frequent consequence of right hemisphere strokes. It is a perceptual problem and the term describes the behaviour of patients who appear to be unaware of visual stimuli situated on the side opposite the lesion.

[3] Hemianopia is a physiological problem caused by damage to the visual pathway between the eyes and the brain. It results in the loss of half of the visual fields and affects the way patients see objects.

Then there is the complication of shoulder pain. In cases of uni-lateral cerebral damage, only one shoulder may be affected. However, in the less common but more severely disabling case of brain stem stroke with bi-lateral paralysis, pain may affect both shoulders. Post-stroke shoulder pain can be depressing (Gamble, Barberan, Bowsher, Tyrrell, & Jones, 2000), demoralising (Wanklyn, 1994) and disturb sleep (Küçükdeveci, Tennant, Hardo, & Chamberlain, 1996). It can cause the patient to withdraw from active rehabilitation (Braun et al., 1971), which restricts functional recovery (Davis, Petrillo, Eichberg, & Chu, 1977; Van Ouwenaller et al., 1986), compromises the pursuit of leisure activities and reduces quality of life (Poulin de Courval et al., 1990). This may prolong length of stay in hospital and add to the costs of care (Roy, Sands, & Hill, 1994; Roy, Sands, Hill, Harrison, & Marshall, 1995). It is a widely recognised problem as shown by the literature; scores of papers and a number of review articles have been written about it, yet its causes are unclear and it is neither well understood nor well managed (Bender & McKenna, 2001; Griffin, 1986; Turner-Stokes & Jackson, 2002).

2.3 Defining shoulder pain

Shoulder pain is difficult to delineate. Some have tried to list the precise anatomical structures in which pain is felt (Winters, Sobel, Groenier, Arendzen, & Meyboom-De Jong, 1996). However, no sharp lines of distinction separate the shoulder region from adjacent regions such as the neck or the upper arm (Codman, 1934). Because of this, and the possibility of referred pain from the neck and the chest (Neviaser, 1983), a detailed anatomical definition is impractical. A large epidemiological survey found that either a simple verbal report of shoulder pain lasting more than 24 hours, or a pictorial representation of pain shaded around the shoulder complex on a manikin drawing (see Figure 1), could be used to define shoulder pain for clinical and epidemiological purposes (Pope, Croft, Pritchard, & Silman, 1997). Although the Arthritis and Rheumatism Council Epidemiological Research Unit recommends these criteria, their generalisability from a general to a stroke population has yet to be determined.

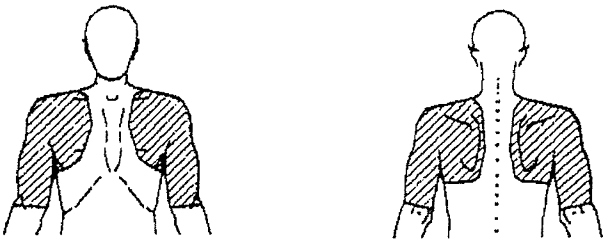

Figure 1: Manikin drawings defining pain felt in and around the shoulder (Pope et al., 1997)

2.3.1 Occurrence of shoulder pain

The estimated annual incidence of shoulder pain in western general populations is 1% to 2.5%, with a prevalence of 7% to 26% (Croft, 1993; Van der Heijden, van der Windt, & de Winter, 1997). In most cases the condition is self limiting, lasting for less than three months (Van der Windt, Koes, de Jong, & Bouter, 1995). By comparison, the incidence and prevalence of post-stroke shoulder pain are harder to ascertain, as it is not always clear which is being reported. Its occurrence has been stated to range from 9% to 84%, but little is known of its duration. The characteristics of included patients, the context of care, methodological differences between studies, the timing of pain assessment and the assessments used may explain differences in these estimates.

Table 1 (pages 9 and 10) lists studies that estimate the occurrence of pain. Some data refer to adults admitted to rehabilitation some weeks after stroke onset (Bohannon, 1988; Bohannon, Larkin, Smith, & Horton, 1986; Jespersen, Jørgensen, Nakayama, & Olsen, 1995; Ring, Feder, Berchadsky, & Samuels, 1993) and some to selected groups comprising older patients (Poulin de Courval et al., 1990; Wanklyn, Forster, & Young, 1996), those with severe upper limb paralysis (Najenson, Yacubovich, & Pikielni, 1971) and those with moderate to severe disability (Sackley & Dewey, 2001). Other studies have included patients with head injuries and tumours (Van Ouwenaller et al., 1986), or excluded patients with more severe complex strokes (Davenport et al., 1996), making cross comparison difficult. Only two have included patients in residential care or who remain at home along with those admitted to hospital at the time of stroke onset (Brocklehurst, Andrews, Richards, & Laycock, 1978; Ratnasabapathy et al., 2003).

Some clinicians maintain that shoulder pain is preventable if the 'right care' is given (Davies, 2000; Johnstone, 1987; Shepherd & Carr, 1998), so differences in the context and quality of care may further explain the discrepancy between findings. Although evidence to support this belief is limited, patients on a rehabilitation unit coming from some referring hospitals had consistently lower rates of shoulder pain than others (Ring et al., 1993). This was so when other factors such as age and time since onset were taken into account, the implication being that patients were better cared for in these settings. Wanklyn et al. (1996) found shoulder pain to increase after discharge home, being common in patients needing help for transfers and those whose arm had been pulled by carers, a finding endorsed by Ratnasabapathy et al. (2003).

Table 1:

Studies citing occurrence of shoulder pain in samples of consecutively admitted stroke patients

First author (year)	N	N (%) with pain	Patient characteristics	Methodology	Timing of assessments	Pain measures
Najenson (1971)	32	27 (84%)	Rehabilitation in-patients selected for severe upper limb paralysis	Assessment once on admission	Average 15 weeks post onset	Presence of pain classified as moderate / severe
Brocklehurst (1978)	135	21 (16%) 58 (43%)	Unselected patients with first stroke at home or in hospital and followed up after D/C	Prospective longitudinal study	Onset up to one year	Present / absent from clinical examination
Bohannon (1986)	50	36 (72%)	In-patients admitted for rehabilitation	Retrospective review of records	Not stated	Fugl Meyer 3-point scale; pain on movement
Van Ouwenaller (1986)	219	157 (72%)	Unselected patients on acute and rehab wards followed up after D/C	Prospective longitudinal study	Onset to 48 weeks	Present / absent from clinical examination
Bohannon (1988)	30	24 (80%) 27 (90%)	In-patients admitted for rehabilitation	Assessment on admission and discharge	4 weeks adm 10 weeks D/C	Ritchie Articular Index: 4-point scale; pain on movement
Poulin de Courval (1990)	94	45 (48%)	In-patients admitted to a geriatric rehabilitation centre	Assessment once on admission	Average 6 weeks	Present / absent from clinical examination
Ring (1993)	80	43 (53%)	Unselected in-patients admitted for rehabilitation	Assessment once on admission	Average 4 weeks	Present / absent at rest or on active or passive movement
Roy (1994)	76	55 (72%)	Unselected in-patients admitted to acute medical and geriatric wards	Prospective longitudinal study	Weekly; onset to 12 weeks	Clinical examination and pain assessment using VAS or verbal rating on 0-10 scale

Table 1 (continued):

First author (year)	N	N (%) with pain	Patient characteristics	Methodology	Timing of assessments	Pain measures
Jespersen (1995)	173	38 (22%)	In-patients requiring prolonged rehabilitation	Retrospective weekly review of records	Not stated	Present / absent from spontaneous report
Davenport (1996)	607	27 (4%)	Consecutively admitted patients to hospital excluding SAH	Prospective review of records	Unspecified	Required analgesia on ≥ 2 consecutive days
Wanklyn (1996)	108	69 (64%)	Aged over 60 with post stroke disability and about to be D/C home	Prospective longitudinal study	On D/C then 8 and 26 weeks later	Presence of pain from interview and on movement
Price (2000)	95	52 (55%)	Consecutively admitted in-patients able to self report on pain.	Prospective longitudinal study	1 week then 1,3 and 6 months post onset	Present / absent from structured interview` and self-report
Langhorne (2000)	311	28 (9%)	Unselected patients on acute and rehab wards followed up after D/C	Prospective longitudinal study	Weekly onset to D/C, and 6, 18, 30 months	Required analgesia on ≥ 2 consecutive days
Sackley (2001)	122	59 (48%)	Adult survivors with a Barthel Index of <11/20 three months after stroke	Prospective longitudinal study	3, 6 and 12 months post onset	Present / absent from subjective report or observation
Gamble (2002)	123	52 (40%)	Unselected in-patients admitted to single site teaching hospital	Prospective longitudinal study	2 weeks, 2,4 and 6 months post onset	Present / absent from clinical examination and site of pain marked on body diagram
Ratnasabapathy (2003)	1349	529 (39%)	Unselected patients in hospital, in residential care or at home	Population based case-cohort study	1 week, 1 month and 6 months post onset	Patients or proxys reported pain on interview at each time point

It might be expected that greater consensus about occurrence would be revealed by the three studies that prospectively investigated unselected patients consecutively admitted to hospital at the time of stroke (Gamble et al., 2002; Langhorne et al., 2000; Roy et al., 1994). However, even in these similar cohorts, estimated incidence varies from 9% to 72%, possibly because varied methods of pain assessment were used and the frequency and timing of assessments differed in each study.

The lowest estimate of 9% comes from a large multicentre study set up to determine the frequency of a range of symptomatic complications up to 30 months after stroke (Langhorne et al., 2000). A record of analgesia in the medical notes on at least two consecutive days established the presence of shoulder pain. However, patients with shoulder pain do not all take analgesics (Broeks et al., 1999) and besides, some patients will doubtless have had aphasia, so pain may have been under reported in this group (Kehayia et al., 1997). Furthermore, since the standard of note keeping has been cited as a methodological problem in a similar study (Davenport et al., 1996), this low estimate should be interpreted with caution.

Gamble et al. (2002) carried out the most comprehensive clinical examination and pain assessment at four time points over six months. They based their operational definition on the criteria recommended by Pope et al. (1997): 'Pain lasting 24 hours since stroke and marked on a pain diagram within a predetermined shoulder area.' They included patients with aphasia, evaluating their shoulder pain by observation and interviews with carers and nurses. Their finding of 40% of patients having shoulder pain at some point during the six months after stroke onset agreed with 39% found by Ratnasabapathy et al. (2003) over the same time scale, though this cohort included patients remaining at home and in nursing homes. A slightly higher proportion of 55% was found by Price, Curless, & Rodgers (2000), though they excluded patients unable to indicate pain reliably.

Noting incidence at distant time points may underestimate the proportion who experience pain, which could explain why Roy et al. (1994) found a higher proportion of 72%, since they carried out weekly assessments over twelve weeks. They found incidence to increase over time, as did Brocklehurst et al. (1978), who found it to range from 16% at two weeks to 43% at one year. Similar trends: 24% at week one to 38% at six months (Price, 2003) and 17% at week one to 23% at six months (Ratnasabapathy et al., 2003) have also been shown.

Roy et al. (1994) went on to postulate that shoulder pain could be a marker of stroke severity, a view supported by Ratnasabapathy et al. (2003). In a group of 122 adults surviving severely disabling stroke for over three months, 48% were found to experience pain during the first year (Sackley & Dewey, 2001). And a very high estimate of 84% came from a small selected group of 32 with severe upper limb paralysis (Najenson et al., 1971). Few authors have explored this hypothesis further, though an inter-relationship between time since stroke, decreasing range of shoulder movement and severity of shoulder pain has been shown (Bohannon et al., 1986).

In summary, with an estimated 40,000 survivors per year left with a residual disability after a first stroke in the U.K., and given the estimates from recent prospective longitudinal studies, around 20,000 patients may well endure the misery of shoulder pain at some point during the year following their stroke.

2.3.2 Postulated causes of shoulder pain

From a demographic standpoint, post-stroke shoulder pain appears to be independent of age and sex (Bohannon & LeFort, 1986; Braus, Krauss, & Strobel, 1994; Cheng, Lee, Liaw, Wong, & Hsueh, 1995; Gamble et al., 2002; Roy et al., 1994) but beyond this, there is agreement about only a few aspects, with most remaining inconclusive or controversial.

Conditions thought to cause shoulder pain broadly divide into: syndromes of central origin, localised physical impairments affecting joint biomechanics and pathological changes affecting the shoulder joint and surrounding soft tissues. Contributory psychological factors comprise disorders of cognition and mood. Physical factors have received far greater attention in the literature than psychological factors, which probably reflects the widespread assumption that shoulder pain has a predominantly physical cause. Evidence to support or refute localised physical causes has been comprehensively examined in a number of review articles over the past two decades. Rather than revisit this work, its conclusions will be summarised. Psychological factors will be considered in greater detail as little has been written about their influence on post-stroke shoulder pain. This is surprising, as pain is a complex blend of sensory, affective and behavioural qualities (Syrjala & Chapman, 1984). Moreover, stroke patients often have sensory, affective and behavioural impairments (Riddoch, Humphreys, & Bateman, 1995) and stroke has severe long-lasting emotional and social consequences (Kelson et al., 1999).

2.3.2.1 Syndromes of central origin

Some pain syndromes are thought to have a central origin. As it is important to differentiate them from other painful shoulder conditions, they are mentioned here.

Central post-stroke pain is a distinctive but relatively uncommon syndrome, the only prospective unselected epidemiological study carried out citing an incidence of 8.4% (Andersen et al., 1995). As its causal lesions are thought mainly to involve the thalamus, it is also referred to as thalamic pain. Pain is generally diffuse, usually involves the whole of the affected side and is felt as a burning pain, often associated with dysaesthesia[4] and hyperpathia[5]. Although pain may be felt in the shoulder, it is unrelated to movement at the shoulder. It is thought that altered sensory input from the periphery or central damage can result in changes in sensory 'tone' leading to increased perception of pain, which may present as constant pain, or allodynia[6] (Boivie, 1999).

Reflex Sympathetic Dystrophy (RSD), also called 'shoulder hand syndrome', has been found to occur in 12.5% to 28% of patients (Davis et al., 1977; Van Ouwenaller et al., 1986). RSD usually appears several months after stroke and clinical criteria for diagnosis include severe pain, hyperaesthesia[7], vasomotor disturbance, oedema and atrophy in the skin and muscle of the shoulder and hand. There is frequently pain and limitation at the shoulder, wrist and finger joints (Davis et al., 1977). Some attribute RSD to peripheral triggers, such as immobility and decreased sensory input, causing an imbalance in central neural control of the sympathetic system (Bonica, 1973). Others suggest the central lesion may be responsible (Eto, Yoshikawa, Ueda, & Hirai, 1980).

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[4] Dysaesthesia is an unpleasant abnormal sensation, whether spontaneous or evoked.

[5] Hyperpathia is characterised by an abnormally painful reaction to a stimulus, especially a repetitive one.

[6] Allodynia is pain due to a stimulus that does not normally provoke pain (e.g. touch or warmth).

[7] Hyperaesthesia is an increased sensitivity to normal stimulation.

2.3.2.2 Localised physical causes

Pain is widely attributed to the diverse and evolving physical changes that occur in the upper limb after a stroke and evolve over time (see section 2.2.1, page 5). Weakness and loss of active movement together with hypotonia or hypertonia renders the arm heavy or stiff and uncomfortable to move. Hypotonia combined with weakness may cause subluxation[8], which some claim to be a cause of pain (Ring et al., 1993). Conversely, hypertonia can contribute to malalignment of the shoulder joint in other directions. In this case, pain is thought to be caused by overactive muscles exerting sustained traction on the site of attachment between muscle and bone, which is well supplied with sensory receptors (Boyd et al., 1993; Braun et al., 1971). Pathological changes in and around the joint may also occur (Bruckner & Nye, 1981) and secondary trauma can further complicate the clinical picture (Jensen, 1980).

Seven review articles, which between them critically evaluate the scientific literature to date, agree that evidence of relationships between post-stroke shoulder pain and severity of paralysis, subluxation, and tears of the rotator cuff[9] is inconclusive. There is a trend towards support for a relationship between pain and reduced range of movement; notably lateral rotation[10], hypertonia and adhesive capsulitis[11]. It has been suggested that the first two impairments contribute towards development of the third (Bender & McKenna, 2001; Griffin & Reddin, 1981; Griffin, 1986; Roy, 1988; Turner-Stokes & Jackson, 2002; Van Langenberghe et al., 1988; Wanklyn, 1994). Poor positioning and

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[8] Subluxation generally refers to an inferior (downward) dislocation of the shoulder joint. It is caused by a decrease in muscular support of the shoulder as a result of paralysis or reduced tone. Gravity causes the soft tissues surrounding the joint to stretch so that the humerus drops out of alignment against the glenoid cavity of the scapula. Subluxation also occurs anteriorly and medially as a consequence of persistent abnormal pull from hypertonic muscles.

[9] The musculo-tendinous sheath surrounding the shoulder joint is known as the rotator cuff. It blends with the fibrous joint capsule and confers stability to the joint. It is vulnerable to damage, both through the degenerative changes associated with age, and as a consequence of being compressed or torn through abnormally forced movements occurring at an unstable paralysed joint.

[10] When the elbow is at the side and the forearm held across the front of the body, the humerus or upper arm is in medial rotation. Lateral rotation occurs when the forearm is moved in a horizontal plane so that the hand points forwards. During this movement, rotation of the humerus occurs at the shoulder joint.

[11] Adhesive capsulitis, commonly known as frozen shoulder, is characterised by pain and stiffness which may result in contracture of the fibrous capsule surrounding the shoulder joint.

careless handling of the paralysed shoulder are also cited as contributing to pain by these authors and others (Andersen, 1985; Forster, 1994; Jensen, 1980; Rathfon, 1994; Ratnasabapathy et al., 2003; Varghese, 1981), though only anecdotal evidence has been presented to support this belief.

2.3.2.3 Disorders of perception and cognition

Patients with right hemisphere (or non-dominant) strokes are liable to have disordered perception which may go undetected (Mulley, 1982). Joynt (1992) suspected that this might play a part in the pathogenesis of post-stroke shoulder pain. He found a higher incidence of pain in patients with right hemisphere strokes, but poor relief of pain after local anaesthetic injection into their shoulders. He posed two theories. Firstly, that patients with visuospatial neglect may not protect their paralysed upper limb effectively, thus being at greater risk of trauma. Secondly, that disturbed pain perception might affect the interpretation of sensory input to the brain, causing nociception, the process that translates sensory input into the experience of pain, in the absence of local pathology.

Neglect is commonly associated with damage to the parietal lobe of the right hemisphere (Halligan et al., 1989; Patel & Taylor, 1999). Broeks et al. (1999) found shoulder pain to be significantly more common in patients with right hemisphere strokes, as did Ratnasabapathy et al. (2003) and Davis et al. (1977) in a group who went on to develop RSD. Though also found by Poulin de Courval et al. (1990), they did not reveal a relationship between pain and the presence of left sided neglect. However, neglect may resolve within a few weeks after stroke onset (Cherney & Halper, 2001). Testing in the study carried out by Poulin de Courval et al. (1990) took place four to five weeks after stroke, so some patients may have had neglect early on that predisposed to shoulder trauma, but which had resolved by the time of testing.

On the other hand, Jespersen et al. (1995) found that neither laterality nor neglect at the time of admission to rehabilitation was associated with pain. However, pain was assessed by patients' 'spontaneous report' and no account is given of how it was determined in dysphasic patients so the number with pain could have been underestimated. Since others have also failed to show a relationship between pain and side of stroke (Bohannon & LeFort, 1986; Bruckner & Nye, 1981; Cheng et al., 1995), the theory associating shoulder pain with neglect has yet to be verified. However, it would be profitable to explore the relationship between the development of shoulder pain and patients' inability to protect and monitor their arm position. This could occur as the result of other cognitive deficits, such as memory loss and confusion which are common in patients with neurological damage (Dombovy, Drew-Cates, & Serdans, 1998; Tate, 1997).

Misinterpretation of sensory input is the second theory proposed by Joynt (1992) to explain his anomalous findings but again, evidence to support a link between disordered sensory processing and shoulder pain is scarce. It is widely recognised that even in the general population, injury can occur without nociception and vice versa (Melzack & Wall, 1988). Furthermore, three main sensory syndromes have been described after parietal stroke, two including impairment of pain sensation (Bassetti, Bogousslavsky, & Regli, 1993). Impaired nociception in the face of a noxious stimulus was demonstrated in a single case report of a patient with a right-sided middle cerebral artery infarct and without cognitive or language deficits. Despite motor loss resolving in a few hours, the patient was left with left-sided sensory deficits. When pain thresholds on both left and right sides were investigated by applying controlled selective thermo-nociceptive stimuli, the patient described a clearly unpleasant feeling, but was unable to describe the quality, localisation or intensity of pain (Ploner, Freund, & Schnitzler, 1999). It is debatable whether the deep pain associated with pathological joint damage would have been perceived in the same way as the superficial pain induced in this experiment.

Investigating a different sensory phenomenon, the unpleasant sensation of coldness in the affected arm, no association was shown with shoulder pain (Wanklyn, Forster, Young, & Mulley, 1995). In contrast, others have shown a statistically significant association between shoulder pain and upper limb sensory impairment; specifically deficits of light touch and temperature (Gamble et al., 2002). Again, the literature on this is scarce and warrants further research. The significance of these findings is to highlight the uncertainty that may accompany stroke patients' reports of the presence or absence of shoulder pain and the need for regular assessment to monitor sensation and thus to identify patients who may be at risk of developing pain.

2.3.2.4 Disorders of mood

Depression, emotionalism, low morale, anxiety and confusion are all common after stroke (Davenport et al., 1996; Langhorne et al., 2000; Mulley, 1982). Given the relationship between pain and depression in the non-stroke population (Merskey, 1999), and the increasing likelihood for stroke patients to develop both over time, it would be surprising to find no link between them. This relationship was investigated by Savage & Robertson (1982), but their finding of an association was based on proxy ratings of both shoulder pain and depression made by patients' physiotherapists, which introduced an unacceptable bias. Since then, only two studies have investigated this. One used the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) and found a significant relationship two weeks after onset of stroke but not at six months (Gamble et al., 2002). The other used the Nottingham Health Profile (NHP) (Hunt, McEwan, & McKenna, 1986) and reported a trend towards an association later on (Wanklyn et al., 1996). A third found an association between shoulder pain and social isolation, emotional reaction and energy levels; also rated on the NHP (Küçükdeveci et al., 1996).

Though needed, further research into associations between shoulder pain, depression and anxiety may be hampered by the difficulty that patients with language deficits may have in using instruments such as the HADS and the NHP. In the only randomised trial to include a measure of affective response to shoulder pain, a simple four-point scale was used ranging from *0: Pain does not bother me at all* to *3: Pain bothers me a great deal* (Partridge, Edwards, Mee, & Van Langenberghe, 1990). This study compared two different treatments for post-stroke shoulder pain and found that though pain severity was related to affective response for the group as a whole, in individual cases this was not always the case. In this study, patients with aphasia were excluded, but it is possible that the inability to communicate in the face of pain could increase anxiety further.

Fear of pain, manifested by avoidance of movement, plays a significant part in the development and maintenance of chronic pain behaviour in general musculoskeletal conditions (McCracken, Zayfert, & Gross, 1992; Vlaeyen & Linton, 2000). If, as has been hypothesised, careless handling has contributed to the genesis or exacerbation of shoulder pain in some stroke patients, fear may well be a significant factor in on-going pain and contribute to withdrawal from treatment (Philips, 1987). This possibility has not been investigated in the literature.

To summarise so far, many questions remain unanswered. The prevailing view is that post-stroke shoulder pain has a mainly physical cause, though evidence to support associations between physical factors and pain is inconclusive. The part that psychological factors play is uncertain. Some authors have criticised the pain assessments used in research studies. These will now be reviewed but first, the purposes of assessment are outlined.

2.4 Assessment

Assessment is crucial to our understanding of medical conditions. It is fundamental to clinical examination and to the evaluation of health outcome. Pain assessment involves obtaining information from a patient for a specific purpose and takes a number of forms. At its simplest level, determining the presence or absence of pain is enough for case ascertainment. Alternatively, identifying its salient features along with other signs and symptoms informs diagnosis. Deciding on an appropriate intervention may depend on the severity and timing of pain. Finally, recording outcome to monitor progress and evaluate change requires sensitive measures of one or more aspects of pain. As such, assessments are tools and processes which should be used with a clear aim in mind (Wade, 1992). Measures in a narrower sense are integral to assessment, being used to grade specific variables of interest. In the context of pain, a measurement scale can rate a single dimension, for instance intensity, as mild, moderate or severe; alternatively, more complex constructs such as pain-related fear and anxiety are measured across multiple domains using detailed questionnaires (McCracken et al., 1992).

The biomedical research literature is underpinned by assessments and measures, through which patient characteristics are described and statistical inferences made. Indeed, the credibility of such research rests on the suitability of the instruments used. Those described here have a variety of aims. Firstly, to determine the presence of pain for case ascertainment, secondly, to describe 'measurable' components of pain, such as intensity, for outcome measurement in intervention studies and thirdly, to describe the characteristics of pain in exploratory studies. There is some overlap between them.

2.4.1 Clinical examination for diagnostic purposes

In the general population, clinicians base their diagnosis of shoulder conditions and subsequent management on knowledge gained from a rheumatological or orthopaedic clinical examination. This covers three areas. Firstly, a history of the patient's pain from a self-reported account of its timing, distribution, intensity and sensory qualities, together with its aggravating and relieving features. Secondly, an evaluation of physical presentation; evidence of swelling, postural asymmetry, range of active and passive movement, muscle weakness and functional limitations, gained through observation, palpation and manual testing. Thirdly, information about pathological change from X-rays and/or other tests (Bamji, Erhardt, Price, & Williams, 1996; Kaergaard, Andersen, Rasmussen, & Mikkelsen, 2000). Thus assessing the painful shoulder involves pooling information from patient and clinician. Diagnosis is arrived at using clinical expertise founded on systematic analyses or algorithms of pain history and physical presentation (Neviaser, 1983; Turner-Stokes, 1996; Uhthoff & Sarkar, 1990).

In the stroke population, each of these sources of information may be compromised. For example, memory loss, aphasia and sensory impairments confound giving a history and describing the characteristics of pain (Joynt, 1992). Active movement may be absent or abnormal in patients with paralysis and furthermore, in a non-verbal patient it may not be clear whether movement is compromised by weakness or limited by pain. Assessments based on shoulder function are unsuitable in the non-functional upper limb. Therefore clinicians often have to base their opinion on less knowledge or ambiguous findings. No criteria have been defined to assist in the diagnosis of post-stroke shoulder pain, nor is there any consensus as to what information about the characteristics of pain should be sought from patients.

Only one study was found that investigated clinical assessment (Vanspall, Richardson, & Moreland, 1996). A modified Delphi survey was used to identify variables that expert physiotherapists regarded as important when assessing stroke patients with shoulder pain. This generated a comprehensive set of impairment and disability variables for assessing the areas of diagnosis, evaluation and prediction of shoulder pain after stroke, but did not delineate which aspects of pain itself should be measured.

2.4.2 Analysis of pain assessments used in research studies

To identify measures used to assess post-stroke shoulder pain in the research literature, searches in Embase (1980-2003), Medline (1977–2003) and the Allied and Complementary Medicine Database (1985-2003) were carried out using the following search terms in combination: Shoulder pain; assess* or measure*; stroke or hemipleg* or hemipare*. Additional references were identified from published review articles from Europe (Bertoft, 1999; Forster, 1994; Snels et al., 2002; Turner-Stokes & Jackson, 2002; Van Langenberghe et al., 1988; Wanklyn, 1994), North America (Andersen, 1985; Griffin & Reddin, 1981; Griffin, 1986; Rathfon, 1994; Varghese, 1981) and Australasia (Bender & McKenna, 2001; Roy, 1988; Shepherd & Carr, 1998). An analysis of 59 studies in which pain assessments were described revealed 20 different types of measure used either singly or in combination. These are listed in Table 2 below and further described in the following sections.

Table 2:

Assessment measures used in studies investigating post-stroke shoulder pain

Description of assessment	Number of studies (N=59)	(%)
Presence or absence		
Presence or absence (no criteria given)	6	(10)
Requirement for analgesics	6	(10)
Spontaneous report by patient	2	(3)
Timing		
Pain duration (time since onset)	8	(14)
Frequency or timing of pain episodes	5	(8)
Location		
Location (sites marked on self or diagram)	7	(12)
Tender areas on palpation	7	(12)
Scaled measures		
Severity/intensity in general	25	(42)
Visual analogue scale	13	(22)
Verbal rating scale	12	(20)
Other nominal or ordinal scale	8	(14)
Numeric rating scale	4	(7)
Circumstances		
Pain at rest and/or on movement	28	(47)
Pain at the end of shoulder lateral rotation	14	(24)
Pain at night	5	(8)
Pain behaviours		
Observed expression of pain	5	(8)
Ritchie Articular Index	4	(7)
Other measures		
Interview and/or verbal description	10	(17)
Subjective report by patient, carer or staff	7	(12)
Questionnaire	5	(8)

2.4.2.1 *Clinical examination*

Some describe using a clinical examination to screen patients for shoulder pain, though it is not always clear how pain itself has been evaluated. The most explicit accounts come from studies investigating RSD, which define diagnostic criteria including pain and loss of range in specified shoulder movements, as well as severe pain and tenderness of the shoulder, wrist and fingers (Braus et al., 1994; Davis et al., 1977; Tepperman, Greyson, Hilbert, Jimenez, & Williams, 1984; Van Ouwenaller et al., 1986). Others simply describe their examination as physical (Joynt, 1992; Rizk, Christopher, Pinals, Salazar, & Higgins, 1984) or physical and neurological (Chantraine, Baribeault, Uebelhart, & Gremion, 1999; Cheng et al., 1995; Gamble et al., 2000; Price et al., 2003; Ring et al., 1993).

Clinical examinations have also been conducted in conjunction with more specific pain measures that include combinations of the following: analgesic use, pain frequency and/or duration, location marked on the body or on a diagram, tenderness on palpation, intensity using a variety of scales, pain at rest, on movement or at night, observed expressions of pain, verbal descriptors and questionnaires. However, there is little consistency in measures between studies and their purpose is not always clear.

A comment on exclusion criteria is pertinent here. Patients with communication or cognitive deficits have been excluded from about a third of the identified studies. None describe using formal tests to define cut off points for exclusion, but describe criteria such as; *'inability to follow instructions'* (Bohannon et al., 1986; Kobayashi, Onishi, Ihashi, Yagi, & Handa, 1999), *'unable to give informed consent'* (Hanger et al., 2000), *'presence of dementia, dysphasia and confusion'* (Jespersen et al., 1995), *'inability to use a pain measure'* (Dean, Mackey, & Katrak, 2000; Linn, Granat, & Lees, 1999). Although there is a clear rationale for excluding these patients in most cases, it highlights the selectivity of groups studied and the uncertainty that attends the assessment of shoulder pain in more severely affected patients.

2.4.2.2 *Presence or absence of pain*

In some investigations, patients have been selected or categorised for presence or absence of pain only, but the authors do not define their criteria (Brocklehurst et al., 1978; Hakuno, Sashika, Ohkawa, & Itoh, 1984; Lee & Khunadorn, 1986; Moskowitz, Goodman, Smith, Balthazar, & Mellins, 1969). Shai, Ring, Costeff, & Solzi (1984) classified patients on discharge by *'presence or absence of disabling shoulder pain'* but failed to define what they meant by disabling pain. Others grouping patients with pain included those who *'spontaneously reported pain'* (Jespersen et al., 1995) and those *'complaining of pain and/or limitation of movement'* (Nepomuceno & Miller, 1974). Daily observations by a physician and therapists were used in one study; further details were not given (Van Ouwenaller et al., 1986). Where presence or absence was rated in large cohorts of unselected patients (Brocklehurst et al., 1978; Van Ouwenaller et al., 1986), different ways of ascertaining pain in those unable to self-report may have been used, but were not detailed.

2.4.2.3 Analgesic use

In two epidemiological surveys, analgesic use alone defined patients with shoulder pain (Davenport et al., 1996; Langhorne et al., 2000) though as suggested earlier, this may underestimate the proportion with pain. The timing or quantity of analgesic use may reflect levels of pain and has been used in conjunction with other measures. Firstly, to record outcome in a randomised trial of different kinds of electrical stimulation (Baker & Parker, 1986). Secondly, as a comparative measure in a study investigating the relationship of shoulder pain with sleep disturbance (Küçükdeveci et al., 1996). Thirdly, as one of a number of descriptive variables in a study investigating the long-term outcome of arm function (Broeks et al., 1999), though not all patients with shoulder pain used analgesic medication.

2.4.2.4 Frequency, timing and/or duration

Frequency and duration of pain feature in a few descriptive studies, though some terminology is subjective and not clearly defined. Wanklyn et al. (1996) noted that some patients had pain *'only occasionally'* as opposed to others who had pain *'all the time'* and Broeks et al. (1999) categorised pain episodes as *'frequent'*, *'sometimes'*, *'never.'* In their results they report the percentage experiencing *'regular pain episodes.'* Joynt (1992) noted whether the course of pain was *'stable, progressing, improving or vague.'* Few studies have investigated duration of pain, other than to evaluate the time taken for the pain to resolve with treatment (Davis et al., 1977; Dekker, Wagenaar, Lankhorst, & de Jong, 1997).

In a randomised trial evaluating two physiotherapy interventions, Partridge et al. (1990) used a five-point frequency rating of 0*: Not at all*, to 4*: All the time* as an outcome measure but collapsed these to three categories to reflect the clustering of scores given by patients: 1*: Only occasionally or not at all.* 2*: A lot or quite a lot of the time.* 3*: All or most of the time.* This appeared to be a sensitive measure to change, being the only one to show a statistically significant difference between patients in the two treatment groups.

2.4.2.5 Pain location marked on the body or on a diagram

Location has been included in a clinical examination and as a descriptive measure on its own, but there is little agreement in the areas chosen to classify it. The predetermined area defined by Pope et al. (1997), shown in Figure 1, page 7, was used by Gamble et al. (2002). In a similar study, Price (2003) noted pain on a body diagram divided into five broad zones: the anterior, posterior and lateral regions of the shoulder, the upper arm down to the elbow and the arm below the elbow. Broeks et al. (1999) described location, as reported by patients, as being in the shoulder only or in the whole arm, but do not give a precise delineation and Joynt (1992) identified three sites: lateral shoulder, general shoulder and top of shoulder, with radiation to the arm or neck. However, he questioned the validity of using location alone to define pain, finding that only two thirds of a group of 67 patients complaining of pain in their hemiplegic arm located it to the shoulder. Among 28 others with more diffuse pain in the arm, hand or neck or indeterminate area, 18 exhibited shoulder discomfort on examination. He recommended that self-report of location should be coupled with a physical examination to give a more reliable assessment of the presence of pain.

In the only study comparing location with another measure, the site of pain was self-indicated and marked on a pain diagram by the patient (Partridge et al., 1990). Three groups were identified reporting respectively: pain restricted to local areas, more diffuse pain but still restricted to the shoulder region and diffuse pain extending beyond the shoulder region to the arm, neck and trunk. Patients with pain at rest and on movement reported diffuse as opposed to localised pain. Other than in this study, it has not been made explicit by researchers whether pain was marked on a diagram by the patient, or whether proxy markings were made by clinicians from patients' indications of pain location on their own body. Pomeroy et al. (2000) investigated the inter-rater and intra-rater reliability of proxy measures of pain location, using the categories defined by Partridge et al. (1990), together with a further category of no pain. They found reliability to be unacceptably low, and also noted that raters predominantly rated pain in only one of the three categories; diffuse pain radiating away from the shoulder area. Further investigation is recommended to explore reasons for this finding.

2.4.2.6 Tenderness on palpation

Tenderness has been included alongside other measures as an aid to diagnosis of RSD (Roy et al., 1994; Tepperman et al., 1984) or to determine pain during a physical examination (Cheng et al., 1995; Joynt, 1992; Najenson et al., 1971; Poulin de Courval et al., 1990). Leandri, Parodi, Corrieri, & Rigardo (1990) specifically looked for areas tender to pressure over the shoulder as a guide to electrode placement in a study evaluating the benefit of high intensity TENS, an electrotherapeutic intervention hypothesised to have an analgesic effect. Patients made subjective judgements of the efficacy of the treatment, but no defined measure of outcome in respect of tenderness, for example its severity or spread, was used in this or any other studies.

2.4.2.7 Intensity

Almost half of the studies reviewed used some measure of pain intensity, either rated in general or in circumstances such as on movement or at night, though measures vary widely. Verbal and visual analogue scales have been favoured over numeric scales, which were only used in four studies. In one, intensity was rated on a scale of 0-5 (Joynt, 1992), and in three on a scale of 0-10 (Bhakta, Cozens, Chamberlain, & Bamford, 2000; Broeks et al., 1999; Roy et al., 1994).

Verbal measures usually group adjectives in order of severity but it is not always clear whether they have been rated by patients themselves or physicians by proxy. One study reported intensity using the vague description: '*None had pain that could be classified as severe ... some had a little pain.*' (Hurd, Farrell, & Waylonis, 1974). Others are more explicit; the numbers of rating categories ranging from three points to six. However, verbal descriptors vary. For example, none, mild, moderate, severe, very severe and intense was used by Van Langenberghe & Hogan (1988) and none, mild, moderate, distinct, severe, spontaneous by Braus et al. (1994). Severe pain appears in different positions in the hierarchy of terms in these and other studies (Arsenault, Bilodeau, Dutil, & Riley, 1991; Linn et al., 1999; Najenson et al., 1971). In addition, the meaning of the term *'spontaneous pain'*, is unclear. Verbal scales have also been used to rate pain relief according to more descriptive practical criteria. For example, Braun et al. (1971) graded response to surgery in four categories: *1: Significant pain relief in all ranges. 2: Significant pain relief if range of motion restricted. 3: Minor pain relief to tolerable levels for continuing general rehabilitation program. 4: Poor pain relief and symptoms unchanged.*

Thirteen investigations used a visual analogue scale (VAS), which most commonly requires approximation of pain on a 10 cm line anchored at each end by 'no pain' and 'pain as bad as it could be'. One used a 15 cm VAS (Kobayashi et al., 1999), otherwise 10 cm scales were used. In some they were orientated vertically to minimise the effect of unilateral neglect (Dekker et al., 1997; Hanger et al., 2000; Roy et al., 1994), in others the orientation was not specified. Various circumstances have been rated in this way including shoulder pain at rest and on movement (Ikai, Tei, Yoshida, Miyano, & Yonemoto, 1998; Roy et al., 1994), and the degree of pain during normal daily activity (Zorowitz, Hughes, Idank, Ikai, & Johnston, 1996). One group asked the question, *'How would you rate the pain in your left/right shoulder as experienced over the last 24 hours on this line?'* (Hanger et al., 2000). Since pain may only occur occasionally and vary according to circumstances, this measure alone may be insufficient.

The validity and reliability of VAS ratings made by stroke patients, many of whom find this method conceptually difficult, has been questioned (Gamble et al., 2000; Price et al., 1999). However, some have justified its choice by excluding patients with aphasia if it was thought they would be unable to use it (Chae & Hart, 1998). Proxy ratings have been made by staff on behalf of patients, though this may bias the accuracy of scores. In one trial, patients indicated pain by pointing to a position on a 10 cm line (Dean et al., 2000) and in another, patients with aphasia or left sided neglect were helped to fill out their VAS by a therapist (Chantraine et al., 1999). Finally, proxy estimates of patients' pain intensity made by therapists using a VAS have been found to be unreliable. Whereas intra-rater reliability was acceptable, a large systematic bias between raters was found, which would contraindicate using this method until further research has established whether a standardised assessment procedure, or training in the interpretation of pain behaviour, would rectify this problem (Pomeroy et al., 2000).

2.4.2.8 Pain at rest or on movement

In about half the studies, pain was rated either at rest, or on movement, or both. Some simply noted the presence or absence of pain on movement in various directions for case ascertainment (Davis et al., 1977; Tepperman et al., 1984; Van Ouwenaller et al., 1986). Others noted presence or intensity in these circumstances as an outcome measure in investigative or experimental studies (Hall, Dudgeon, & Guthrie, 1995; Küçükdeveci et al., 1996; Kumar, Metter, Mehta, & Chew, 1990; Poulin de Courval et al., 1990; Ring et al., 1993; Rizk et al., 1984).

A three-point scale of pain felt during passive motion at the shoulder in four directions: *0: Pronounced pain during all the movement or very marked pain at the end of range. 1: Some pain. 2: No pain*, is included in a generic physical performance measure for patients with hemiplegia (Fugl-Meyer, Jääskö, Leyman, Olsson, & Steglind, 1975). Limitation in range of movement is noted separately. Variations on this scale have been used by others; some evaluating range and pain separately and some combining the two. Pain at the end of lateral rotation (see footnote 10 on page 14) has served both as an aid to diagnosis and as an outcome measure (Braun et al., 1971). The range of shoulder lateral rotation measured in degrees at the point of pain (SROMP) using a goniometer is one of the few continuous measures used (Bohannon & Andrews, 1990; Faghri et al., 1994; Hanger et al., 2000; Linn et al., 1999; Partridge et al., 1990; Wanklyn et al., 1996).

2.4.2.9 Pain at night

The only research found that specifically investigated pain at night compared the occurrence and type of sleep problems in a group of stroke patients and a matched control group (Küçükdeveci et al., 1996). Pain was assessed at rest, on active and passive movement and by the NHP, which includes questions about pain. Findings confirmed an association between pain and poor sleep. Others have found night pain to be characteristic of adhesive capsulitis, especially in the early stages (Bruckner & Nye, 1981) and to be one of a collection of signs indicating a rotator cuff lesion (Najenson et al., 1971). It has also been noted if reported by patients (Broeks et al., 1999; Wanklyn et al., 1996).

2.4.2.10 Ritchie Articular Index

The principle of rating pain at the end of shoulder lateral rotation was taken one step further by Bohannon & LeFort (1986). They adapted and tested the Ritchie Articular Index (RAI), originally used by rheumatologists to rate joint tenderness on movement (Bohannon, 1988; Bohannon & Andrews, 1990). The RAI is a four-point ordinal scale: 0: *No pain. 1: Complaint of pain. 2: Complaint of pain and wince. 3: Complaint of pain, wince, and withdrawal.* It is the only behavioural rating scale that has been validated for post-stroke shoulder pain.

This scale tests lateral rotation with patients lying supine and explicit methodological criteria are laid down for its use. It has the advantage of being appropriate for patients who cannot understand questions or complete other scales and it has been shown to have good inter-rater reliability (Bohannon et al., 1986). But it has disadvantages. Firstly, the assumption is made that it could serve as an overall shoulder pain measure, but many patients have pain under different circumstances, such as at rest or at night (Roy et al., 1994; Wanklyn et al., 1996), which this measure cannot determine. Secondly, it cannot distinguish between pain felt when an injured joint is put under stress and discomfort felt when a shortened muscle is stretched. It has, though, been used as an outcome measure in some studies (Ancliffe, 1992; Mackenzie-Knapp, 1999; Parry, Lincoln, & Vass, 1999). It has also been suggested that the RAI could be used interchangeably with intensity ratings made by stroke patients using a VAS (Gustafsson & McKenna, 2003), but as the former is a proxy measure of pain behaviour and the latter a self-report of pain intensity, this is questionable (Jackson, 2003).

2.4.2.11 Questionnaires

No studies were found that used standardised pain questionnaires. Four used pre-determined structured questionnaires (Bruckner & Nye, 1981; Gamble et al., 2002; Leijon, Boivie, & Johansson, 1989; Wanklyn et al., 1996), but these were designed for data collection and to record information about symptoms as opposed to measuring pain outcome.

The NHP has been used to investigate depression (Wanklyn et al., 1996; see section 2.3.2.4, page 17) and night pain (Küçükdeveci et al., 1996; see section 2.4.2.9, page 26). It measures perceived ill health in several domains including pain, and is scored on the basis of yes/no answers to questions such as, *'I have pain at night', 'I have unbearable pain', 'I find it painful to change position'* (Hunt et al., 1986). There is a seven-point pain intensity sub-section in the Chedoke-McMaster Stroke Assessment (Gowland et al., 1993) and a four-point pain intensity scale based on how much pain disturbs sleep in the Stroke Impairment Assessment Set (Tsuji, Liu, Sonoda, Domen, & Chino, 2000), but neither of these generic scales were mentioned in the reviewed literature.

Recognising that some stroke patients retain verbal skills whereas others retain visuospatial skills, the ShoulderQ developed for the ICP that prompted this thesis (see chapter 1, page 3) gives patients a choice of methods for reporting on their pain. Originally, verbal and VAS questions were included as alternatives but a numeric graphic rating scale (Jensen & Karoly, 1992) has now replaced the VAS. The ShoulderQ enables patients to self-report on the overall severity, frequency and timing of shoulder pain and to identify its main aggravating and relieving factors. A screening tool, the AbilityQ, designed to test patients' ability to complete a questionnaire and to judge the help they need for reliable completion of the ShoulderQ, precedes its initial use. Both instruments have demonstrated a moderate level of repeatability in a group of patients expected to have difficulty in completing questionnaires (Turner-Stokes and Rusconi, 2003). Further investigation to evaluate the reliability and sensitivity of the ShoulderQ is in progress.

2.4.2.12 Descriptions of pain and pain behaviour

Comments about pain derived from impressions gained during examination or treatment feature in some investigations that have included patients with communication and cognitive deficits. Observation during examination has established pain in three. In one including dysphasic patients, *'signs of discomfort'* were noted, together with information from interviews of nursing staff and carers (Gamble et al., 2000). In another, either the subjective impression of the patient or observation by a therapist was used to ascertain pain in a cohort with severely disabling stroke (Sackley & Dewey, 2001). A further study simply reports rating *'patients' perceived shoulder pain through subjective reports to nursing and physiotherapy staff.'* (Baker & Parker, 1986).

Researchers have used a diverse collection of other verbal descriptions. For example, *'pain tolerance'* is described as improving with treatment which finally resulted in *'complete or almost complete disappearance of pain'* (Davis et al., 1977). And when evaluating a surgical technique to reduce subluxation associated with pain, improvement was rated by whether pain remained *'persistent'* or by patients' reports of *'satisfaction in regard to relief of pain'* (Pinzur & Hopkins, 1986).

It is interesting to compare the wide range of sensory descriptors given by stroke patients with central pain against the scarcity of descriptors denoting other presentations of shoulder pain. Boivie (1999) lists nineteen qualities of central pain. Among those commonly described are *burning, aching, pricking, lacerating and pressing*. In contrast, beyond describing intensity, the qualities of post-stroke shoulder pain have hardly been mentioned, other than by Joynt (1992), who divided pain into three categories of *'sharp, achy and vague.'* This could be because descriptions are not amenable to scientific analysis or alternatively, because the sensations are difficult to describe.

Observed pain behaviours have not been systematically defined and existing validated pain behaviour measures (reviewed in Chapter 3) do not appear to have been used at all. Nevertheless, pain expression was found useful as an adjunct to verbal self-report in a study comparing three exercise programmes (Kumar et al., 1990), though some patients with severe aphasia and cognitive dysfunction were excluded. To assist those with communication difficulties, yes/no answers were sought in response to questions asking if they had pain at rest or during passive range of motion. Facial expression was also watched. Hecht (1992) rated clinical response to subscapular nerve block by comparing facial expressions, vocalisations and the patient's response to having their arm moved through range before and after the procedure. He was able to judge a benefit by this means, noting that pain appeared to diminish during movement, though some aphasic patients were unable give the impression of benefit.

To sum up, there is no uniformity in the assessments used in research and a comprehensive set of measures has been used by only a few. Some aspects of pain are commonly measured, for instance, intensity and pain at rest or on movement. However, few have investigated dimensions such as location or duration. The validity and reliability of some measures is questionable, especially where used to rate pain in patients with aphasia and cognitive deficits. Although pain has sensory qualities, descriptors are rarely mentioned. Finally, affective components such as anxiety and fear have not been explored. There is a need for consensus on a consistent set of measures that provide the information needed to evaluate shoulder pain in patients with stroke, to define different pain syndromes and to use as outcome measures to research the efficacy of interventions.

2.5 Descriptions of pain in the clinical literature

Turning to textbooks written by clinicians, an alternative approach links possible causes with the pain characteristics presented by patients. These feature descriptive details generally missing from scientific papers. Several theories have been postulated.

Ryerson & Levit (1991) classify pain in four ways: Firstly, joint pain from malalignment, felt as a sharp stabbing pain, present on passive and active movement. Secondly, muscle pain from the lengthening of hypertonic muscle too quickly, or stretching beyond accustomed range, felt as a pulling sensation localised in the muscle being stretched. Thirdly, altered sensitivity of the central nervous system to sensory input, felt as a diffuse, sharp and aching pain localised to the shoulder. Lastly, shoulder-hand syndrome which gives rise to a diffuse aching pain in the shoulder and arm in the early stage, progressing to a painful restriction of movement.

Davies (2000) gives two scenarios. Firstly, pain stemming from a subluxed or malaligned shoulder, which gives rise to a dragging discomfort or ache if the arm is left hanging at the side for too long. Secondly, pain from disruption of normal movement patterns which follows a temporal pattern with three stages: An early stage which starts with a sharp pain at end of range when the arm is moved. If neglected, pain may increase to affect movement through range, ultimately, it may become severe day and night resulting in the patient being unable to tolerate the arm being moved or touched.

One research team identified two distinct types of pain in a group of patients selected for severe paralysis (Najenson et al., 1971). The first, who were most likely to have subluxation associated with a rotator cuff injury, were described as having severe shoulder pain, situated in the shoulder region but radiating down the arm and worse at night. Another group had moderate pain, localised to the shoulder, worse on movement at the shoulder and when the upper limb hangs by the body.

Although these descriptions are very different, this method of categorisation integrates possible causal circumstances with symptoms and may have some advantages over allocating a diagnostic 'label' (Bender & McKenna, 2001).

2.6 The patient's viewpoint

Finally, what of the experience of shoulder pain from the perspective of stroke patients themselves? There is a lack of empirical work in this area. However, two autobiographical books shed a very different light on the experience from that gained in the scientific literature. Pain here is graphically described in the context of its circumstances. Sensory, affective and evaluative descriptors all feature in these accounts which convey the distressfulness of shoulder pain alongside the overall experience of stroke.

Bauby (1997) suffered a massive brain stem stroke, which left him almost totally paralysed, and reflects on aspects of his experience in this extract.

> 'At first some of the staff had terrified me. I saw them only as my jailers, as accomplices in some awful plot. Later I hated some of them, those who wrenched my arm while putting me in my wheelchair, left me all night long with the TV on, let me lie in a painful position despite my protests.' (Bauby, 1997); pages 117-118).

And McCrum (1998) describes his experience two weeks after his stroke.

> 'Even the good nurses have no idea how much they can hurt, how much hurt they can cause by wrenching my left arm, which is still totally paralysed and helpless, at the wrong moment. There's one nurse who causes pain every day.' (McCrum, 1998; page 91).

Apart from the expressions of fear and helplessness, what is particularly striking about these accounts is the apparent discontinuity between these patients' experiences of pain and its recognition by the hospital staff. It raises questions of whether and how information about pain is ordinarily conveyed from patients to staff. Bauby was unable to speak and could only signal by blinking. Did his nurses try to elicit information from him about his pain? Why did McCrum's nurses have no idea how much they could hurt? How many other stroke patients experience pain that goes unnoticed? How is information about pain exchanged between patients and staff?

Two months later, a few days before his discharge, and referring to his wife, McCrum writes:

> 'Sarah was right to identify my left arm as the source of anger and despair. Although it was lifeless, it was not without feeling: at times it could be excruciatingly painful.' (McCrum, 1998; page 170).

Sarah gives a further perspective.

> 'Robert is feeling very sad about his arm, and I am, too. I think I've made my peace with it not coming back. But Robert has to make his peace too. He tosses and turns at night and worries about it, and I think he's doing what I've been doing: using it as a symbol for all of this, the pain of loss, the unfairness of this happening. When I look at our actual situation now, I don't think it's that bad. But the emotions surrounding it are. (McCrum, 1998; page 180).

Again, these brief passages describe the emotional toll of stroke and highlight the complexity of pain. Both Bauby and McCrum may have had physical deficits or pathological changes in their shoulders that started their problems off. It would also appear that handling played a part, if not in its genesis, then certainly in prolonging their pain. Though it is important to research these variables systematically, to separate the physical from the psychological components of the pain experience is likely to confound our understanding of pain since to investigate one without the other can only give a partial picture. It would appear that solutions are being sought for a problem that has not yet been clearly delineated.

2.7 Conclusion

The onset of paralysis, changes in muscle tone and loss of mobility that accompany a stroke leaves the shoulder joint inadequately protected and vulnerable to secondary soft tissue damage from poor positioning and careless handling. A range of physical, psychological and contextual factors may contribute to the experience of shoulder pain, but the relationship between them is not well understood. Moreover, the spectrum of additional impairments that stroke patients present with makes this problem difficult to research. Studies investigating post-stroke shoulder pain have tended to use selected groups of patients and show little consistency in the assessments used to rate pain. Furthermore, there does not appear to be any consensus as to how post-stroke shoulder pain should be defined in terms of its timing or location. The definition suggested by Pope et al. (1997) has only been used in one study (Gamble et al., 2002) and even then, it was found necessary to augment it with observation and interviews with other people to determine pain in aphasic patients.

Clinical assessment of pain entails obtaining information about it from a patient for the purpose of informing management and evaluating progress, but little is known about this process in the context of post-stroke shoulder pain. As the 'stroke literature' is limited in its approach, the next chapter turns to the 'pain literature' to explore theories of pain and its assessment further.

Chapter 3

Pain and its assessment

3.1 Chapter outline

This chapter addresses pain from a more theoretical perspective. To begin with, the nature of pain and its definition is discussed. Then follows an account of how it has been conceptualised in the form of theoretical models; specifically, biomedical, behavioural and psychosocial models of pain. These are considered in the context of stroke. The argument advanced in the last chapter is reinforced; that is that the biomedical model, which has underpinned research into post-stroke shoulder pain to date, has focused too much on peripheral nociception; failing to take into account the psychological and contextual factors which contribute to the overall experience of pain.

The development of systematic pain assessment is then summarised, followed by a critique of the diverse range of rating scales that have been developed for use in both research and clinical settings. A distinction is drawn between self-report and proxy measures, most importantly in relation to their validity. Greater emphasis is given to measures that have not hitherto been used in the context of stroke, but that may have an application, in particular assessments of pain behaviour. The methodologies used to develop them, together with their advantages and disadvantages are discussed.

3.2 The elusive nature of pain

It is indicative of its complexity that pain, something we all experience and recognise so intimately, has been the subject of so much debate about definition and meaning. One reason is that its meanings extend beyond a bodily sense of hurt to incorporate a range of feelings. The emotional pain of grief, despair and distress are all familiar concepts which may, individually or collectively, merge with pain which is associated with a physical injury or a medical condition. These states of pain exist first and foremost as an awareness or introspection and may remain just that, an unpleasant and distressful private experience known only to the individual experiencing it. What discriminates post-stroke shoulder pain from the pain of loss and grief after stroke is that it is associated or described in terms of tissue damage in the shoulder region and as such, fits the formal definition of the International Association for the Study of Pain (IASP) (Merskey & Bogduk, 1994):

> An unpleasant sensory and emotional experience which we primarily associate with tissue damage or describe in terms of tissue damage, or both.
>
> Note: The inability to communicate in no way negates the possibility that an individual is experiencing pain and is in need of appropriate pain relieving treatment.

The IASP Council added the note in 2001 after approval of a recommendation made by the Task Force on Taxonomy. It is an important addition, addressing the objection that the definition did not apply to living organisms that are incapable of self-report, such as infants or people with severe mental impairments (Anand & Craig, 1996).

The IASP definition has been criticised for being too narrow. The word *'unpleasant'* has been said to understate the multiple and complex dimensions of unpleasantness inherent in perceived pain (Melzack & Wall, 1988). Similarly, associating pain to *'tissue damage'* has been deemed restrictive, as such damage is not necessary for pain to exist (Horn & Munafò, 1997). However, if people regard their experience as pain and report it in the same ways as pain caused by tissue damage, as is the case with central post-stroke pain, it should be accepted as pain (Merskey & Bogduk, 1994). Despite being parsimonious, this definition has the advantage of being open to further qualification to enhance its meaning in the context of differing circumstances.

The term '*describe*' could refer to the mental representation or private introspection about the nature of pain as well as to the interpersonal signal, whether verbal or gestural, that conveys information about the experience of pain to another individual. Thus the definition appears to be an holistic one, incorporating both of these related and sequential events. It is logical to phrase the definition to reflect its composite meaning, rather than to have one definition for the raw inner experience of pain and another for its outward expression. This is, after all, what others recognise as 'being in pain', even though it is more accurately described by theorists as expressing pain behaviour (Fordyce, 1984).

It has been argued that the purpose of pain is to act as a survival mechanism by alerting the individual to the presence of tissue damage from the internal or external environment. Pain enhances survival by generating behaviours, one purpose of which is to reduce the pain or damage. Although the capacity to respond to painful experiences is inherent to living beings, the interpretation and meaning of the experience develops through positive and negative experiences. It is also affected by environmental associations and mediated by memory, learning and conditioning as the individual develops from infancy to adulthood (Anand & Craig, 1996).

The relationship between feeling pain and reporting pain is highly context dependent; thus the way people behave when in pain sometimes remains as private as the introspection itself. Prior experience usually tells people whether their pain is 'ordinary' or serious. In the former case, when they comprehend their pain, their behaviour may never be witnessed; they may say or do nothing in the expectation that it will go away. Alternatively, they may use remedies such as analgesics or change their pattern of activity to accommodate the pain. The incidence of unreported pain is unknown, though there is evidence to suggest that many people manage it without seeking recourse to outside help (Pope et al., 1997).

On the other hand, people who are in pain often want to signal its presence to other people in order to obtain help, but unless they have the opportunity to communicate this private experience in a way that others can understand and respond to, they may not receive the help they need (de Rond, de Wit, van Dam, & Muller, 2000). Successful communication depends on another person being alert to expressions of pain and interpreting their meaning, whether this occurs through inference from their behaviour or through inviting them to describe it. This is the closest one can get to understand another person's pain. It is the starting point of assessment and plays an essential part in evaluating the pain problem and informing the provision of appropriate care.

3.3 Models of pain

3.3.1 The biomedical model

Pain is the most frequent reason people seek help from medical professionals (Solomon, 1996; Turk & Melzack, 1992) and the relief of symptoms, of which pain is arguably the most common, is seen as the gold standard of medicine (Diamond & Coniam, 1991). It is not surprising, therefore, that a biomedical model of pain has dominated thinking for so long. This traditional model is based on the premise that integrating findings from a clinical examination with the results of diagnostic tests will lead to an explanation for symptoms and prompt treatment to alleviate them (Rudy et al., 1992). The rationale is that indicators of pain symptoms arise from 'real' or somatogenic problems that can be scientifically determined and influenced by pharmacological and/or physical interventions. However, this leads to the assumption that if no logical explanation for the pain is forthcoming, it must be 'imagined' and construed as a psychogenic problem.

It is indeed the case that many complaints of pain investigated by clinicians can primarily be explained in physical terms as an acute response to injury, pathological change or the consequence of surgery. Tissue damage such as this contributes to pain through nociception and serves an adaptive purpose, to trigger help-seeking behaviour. It is, though, now accepted that the biomedical model has focused too much on peripheral nociception as a cause of pain and has failed to take into account psychological factors, prior life events and social context, all of which contribute to the overall experience of pain. This model also fails to explain pain of a maladaptive nature, as is seen in some patients with chronic pain, who appear to have no physical cause for their pain or whose experience is disproportionate to tissue damage (Gifford, 1998). Thus it is relevant to consider the contribution to understanding offered by the behavioural model.

3.3.2 The behavioural model

A distinction has been made between nociception, which evokes the experience of pain, and the outward expression of that experience in the form of pain behaviour. The behavioural model recognises that pain problems can only be made evident to the outside world through behaviour and thus places pain behaviours as central to the pain construct. The corollary to this is that pain behaviours can be influenced by whatever factors influence behaviours in general, and are therefore open to manipulation through conditioning. Initially respondent or reflex adaptive pain behaviours, such as guarding, may become positively or negatively influenced by contingent reinforcement and become operant behaviours. For example, positive reinforcement in the form of care and attention from others may result in guarding becoming maladaptive; that is continuing to occur to a greater extent than might be expected by the underlying tissue damage. From a therapeutic perspective, non-reinforcement, such as the withdrawal of care and attention during prolonged episodes of guarding, can be used to reduce behaviours such as this that have become maladaptive (Fordyce, 1984).

Thus the critical controlling influence on the way pain is expressed is seen by behaviourists to come from events outside the person. This model explains some behaviours shown by people with chronic pain and has informed the development of useful behavioural rating instruments for this group (Anderson et al., 1987; Keefe & Block, 1982; Keefe, Wilkins, & Cook, 1984; McDaniel et al., 1986) and the design of operant-based treatment programmes (Richards, Nepomuceno, Riles, & Suer, 1982). However, it fails to account for the fact that behaviour can also be controlled to a degree by internal events, such as personality, training and past experience (Huskisson, 1974). Furthermore, because what a person transmits is behaviour not sensations, to understand pain only in terms of its outward expression presents only a partial view of a complex phenomenon (Sternbach, 1968).

Evidence from studies that show poor correlation between measures of pain obtained separately through self-report and observed pain behaviours would support the belief that they tap into different dimensions of the pain experience. Thus a comprehensive pain assessment should comprise ratings of both (Labus, Keefe, & Jensen, 2003; Richards et al., 1982; Wilkie, Keefe, Dodd, & Copp, 1992). Taking this further, it is suggested that overt pain behaviour itself may at one level be a clinical measure of adaptive or illness behaviour and at another, a measure of maladaptive behaviour; the two measuring discrete and different clinical dimensions of pain (Waddell & Richardson, 1992).

The relative significance of self reported pain and observed pain behaviours in the context of different conditions is as yet unclear and they may not have a simple relationship. It has been hypothesised that the greater divergence between them may be a specific feature of chronic pain (Fordyce et al., 1984), a view supported by a study which found closer concordance between nurses observations of pain and patients' self-report in acute as opposed to chronic pain patients (Teske, Daut, & Cleeland, 1983). It is possible that adaptive pain behaviours originating in response to acute physical injury change in nature over time to become increasingly maladaptive. This can be illustrated by the concept of an acute-chronic pain continuum, along which different factors have varying influences over time (Horn & Munafò, 1997). It would be fruitful to explore these relationships more systematically in longitudinal studies, though designing methodologies to do this may present a challenge.

3.3.3 The biopsychosocial model

The recognition that pain is a complex multi-dimensional experience is central to this model, which goes some way towards describing both the intrinsic and extrinsic influences that are integral to the perception of pain. The conceptual background to this model comes from gate-control theory (Melzack & Wall, 1988). When peripheral nerve cells are stimulated by injury, impulses pass to transmission (T) cells in the dorsal horn of the spinal cord. The 'action system' responsible for the pain experience and response to it is triggered when the integrated firing level of T cells reaches or exceeds a critical level (i.e. the 'gate' opens). Impulses then transmit to local reflex circuits and to the brain via the ascending nervous system. Two parallel processing systems, the sensory-discriminative and motivational-affective systems of the brain are thus alerted to nociceptive stimuli; both these systems are in turn influenced by higher central nervous system processes, such as the cognitive evaluation of past experiences and by a range of other psychological and contextual factors. These higher systems have both excitatory and inhibitory influences and project back to the gate control system via the descending nervous system. Accordingly, this model recognises the experience of pain as involving the whole integrated nervous system.

Syrjala & Chapman (1984) illustrate this interactional model in a visual form, which displays the interrelationship of factors contributing to pain (see Figure 2, page 40). The model indicates that nociception is part of private experience and may be amplified or attenuated by a range of influences including cognitive variables, such as attention and emotion (Villemure & Bushnell, 2002), beliefs about cause and control (Arnstein, 2000; Edwards, Pearce, Turner-Stokes, & Jones, 1992) and psychosocial and cultural factors (Frischenschlager & Pucher, 2002). This model is useful in that it not only indicates the variables that may influence the experience of pain but also differentiates between private experience and observable behaviour and the environmental influences which act on it.

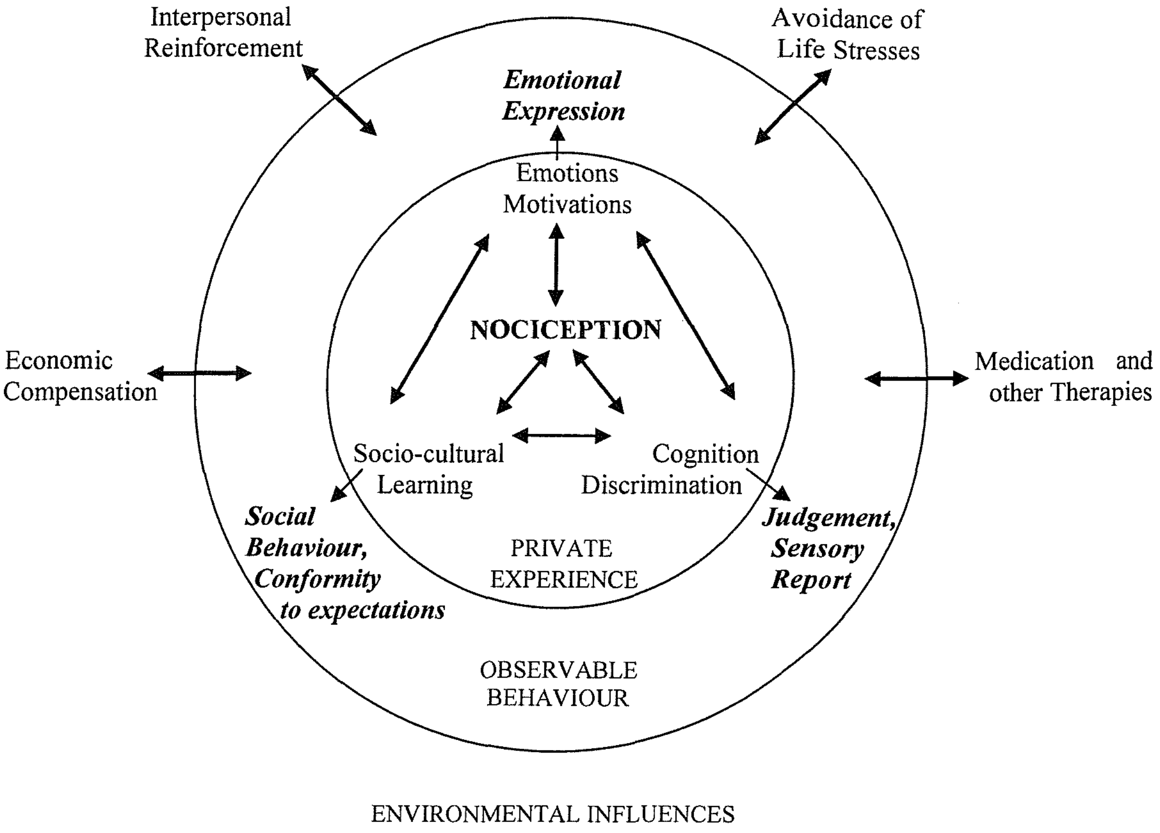


Figure 2: Interactional model of pain (Syrjala & Chapman, 1984; page 73).

3.4 Models of pain in the context of stroke

Stroke is primarily a medically managed condition and post-stroke shoulder pain has traditionally been viewed from a 'biomedical model' perspective as having a predominantly physical origin. As was argued in the last chapter, this model does not adequately explain the problem because it fails to account for the impact that psychological and contextual variables have on pain. However, as there is evidence of pain producing tissue damage in some patients with post-stroke shoulder pain, it is reasonable to assume that pain is an adaptive response to injury, at least to begin with. Thus it is appropriate to base initial management on this notion. The difficulty comes over time when pain persists and recovery from stroke is incomplete. The acute-chronic continuum identified earlier, which could be affected by variable influences over time, may explain some of the discrepant findings from research studies that have looked only at relationships between pain and physical impairments; few clear associations between these have been revealed.

Identifying pain behaviours that are maladaptive in the context of chronic disability that generates its own set of atypical behaviours is a difficult challenge. There are numerous possibilities for misinterpreting behaviours in stroke patients. For example, increased muscle tone gives rise to differential movement patterns, such as stiffness or holding the arm close to the body, yet these have been identified as chronic pain behaviours in other conditions (McDaniel et al., 1986) and could be confused with them. Similarly, avoidance of activity may be an adaptive response to pain but could also be induced by fear of pain (Vlaeyen & Linton, 2000), fear of falling or by disorders of mood.

Indeed, fear and anxiety are but two among many complex environmental and psychosocial variables that may have a potent influence on pain perception and pain behaviour in stroke patients. Finding oneself suddenly and unexpectedly in hospital, perhaps partially paralysed and unable to speak is a traumatic and frightening experience (Burton, 2000; Sundin, Jansson, & Norberg, 2000), which has long term social and emotional consequences (Kelson et al., 1999). Fear and anxiety are known to exacerbate the experience of both acute and chronic pain (McCracken et al., 1992), though it may be difficult to establish the extent of this relationship in stroke patients whose fear and anxiety may be caused by a host of problems in addition to pain.

In brief, both the inner experience of pain and the ensuing behaviour are mediated by a complex blend of physical, psychological and contextual variables. Pain behaviour can be, and is, transmitted in an observable and to some extent, measurable form, which is considered an essential component of pain assessment. The problem comes not only in making the 'right' observations and recording them as measures, but also in interpreting them in the context of individual circumstances. It has already been shown from a review of the 'stroke literature' that an eclectic mixture of assessment measures has been used in research into post-stroke shoulder pain. In the next section, pain assessment will be reviewed from the perspective of the 'pain literature'.

3.5 Systematic pain assessment

The systematic measurement of pain has a short history in the overall context of medicine. During the late nineteenth and early twentieth centuries, pain was believed to originate from the stimulation of superficial and deep sensory organs in the peripheral nervous system and to be mediated by the temporal and spatial features of the applied stimulus. The key questions prompting research were firstly, to identify the anatomy of these organs and their associations with the nervous system. Secondly, to provide evidence for their supposed function by qualifying and quantifying stimuli evoking pain of varying kinds and thirdly, to investigate relationships between stimuli and the behavioural manifestation of perception (Hardy, Wolff, & Goodell, 1952).

The methodologies chosen to answer these questions involved application of a range of thermal, mechanical, chemical and electrical procedures to areas of the body in a laboratory setting. The examples referred to below, along with many others, are comprehensively described by Hardy et al. (1952). The main 'outcome measure' was the subject's first recognition of nociception; that is the pain threshold. Goldscheider, using thermal methods to evoke pain, first investigated this scientifically in 1884. A range of unpleasant sounding experiments followed, including dropping a metal rod from various heights onto a finger held in a clamp, applying an electrical current through a metal tooth filling and distending the gastrointestinal tract by inflation of a swallowed balloon. The first documented measure of pain behaviour involved placing an elliptical metal grater under a sphygmomanometer cuff and noting the pressure at which the subject winced! One notable finding, replicated by a number of researchers, was the wide variability in individual reports of the threshold 'moment of pain'. The disparity between the quantified applied stimulus and its perception has since been explained by pain gate theory (Melzack & Wall, 1988).

Early laboratory work on pain thresholds only required subjects to communicate the presence or absence of pain, but in the 1930s, ordinal verbal scales came into use. More detailed investigation of scaling was carried out to answer questions about sensitivity to noxious stimuli and in clinical settings, to demonstrate the effectiveness of analgesic drugs and to make comparisons between them. Both required more sensitive measures of discrimination than ordinal scales of pain severity, such as mild, moderate and severe, which had been the general currency of pain assessment until that time. In a landmark experiment, known intensities of thermal radiation between threshold and ceiling pain were used to record 21 'just perceptible steps' in intensity of felt pain between the two extremes (Hardy, Wolff, & Goodell, 1947). The dol (two perceptible steps) was adopted as the unit of pain intensity and gave rise to an 11-point scale that was later validated as a ratio measure for the perception of superficial pain using a radiant heat stimulus. The 0-10 numeric rating scale in wide use today reflects this finding.

Whilst revealing some fundamental observations on the nature of pain and the rating of its intensity, laboratory methods had limitations. Firstly, it could not be assumed that participants would display identical responses to similar stimuli in 'real life' contexts and secondly, generalising from artificially induced to pathological pain was unrealistic. In pathological pain the nature of the stimulus is often unknown and emotional factors such as fear and distress can confound rating characteristics such as intensity.

Hewer & Keele (1948), in a series of experiments in both laboratory and clinical settings, explored sensitivity to ischaemic pain, deemed to be closest to pathological pain. Four healthy subjects were able to discriminate about ten grades of intensity, described as 'pain units'. However, it was judged that the fineness of discrimination may have been due to a steady increase of artificially induced pain over a short time and it was accepted that not all pains might be appreciated or remembered with the same degree of sensitivity. In a later study to evaluate the efficacy of analgesics on pathological pain, patients recorded intensity hourly on a pain chart using a five-point scale of 'pain units', giving verbal descriptors ranging from none to very severe. This was regarded as a more realistic clinical measure (Hewer, Keele, Keele, & Nathan, 1949).

Recognition of individual variations in both pain threshold and sensitivity to pain has led to the suggestion that a scale of 'pain relief' or 'change in pain' may be a more useful clinical measure of pain, as patients tend to describe their pain as better or worse in comparison to a previous occasion. In a recent meta-analysis of data from ten placebo controlled drug trials in a range of chronic pain disorders, a consistent relationship was shown between global impression of change and pain intensity reduction. It was concluded that change in pain of 2 points on a 0-10 numeric rating scale represented a clinically important improvement in pain (Farrar, Young, LaMoreaux, Werth, & Poole, 2001; Rowbotham, 2001).

3.6 Self-report

In both research and clinical settings, the most commonly used measure is the self-report scale for rating pain intensity (Huskisson, 1974; Jensen & Karoly, 1992; Syrjala & Chapman, 1984). Useful additional information can also be ascertained through self-report. For example, the location of pain, its qualities and its associations all inform diagnosis. Moreover, its temporal features guide timely prescription of analgesia or other treatments as well as on-going management.

Validated scales used to measure intensity divide broadly into four groups: verbal rating scales (VRSs), numeric rating scales (NRSs), visual analogue scales (VASs) and picture scales, which comprise a sequence of facial expressions representing degrees of pain. Because accounts of their validity and reliability in general populations have been extensively written about elsewhere (Jensen & Karoly, 1992; Melzack & Katz, 1999) and because they were introduced in the last chapter (see pages 24 and 25), the first three will be summarised before being discussed with reference to their suitability for the stroke population. Facial scales are discussed in greater depth as the use of images reflecting pain may have an application in the field of stroke.

3.6.1 Verbal rating scales

These have the advantage of being easy to administer and score and there is good evidence for their construct validity (Jensen & Karoly, 1992). However, some patients may have difficulty in conceptually managing more than five categories due to semantic rather than scaling limitations and ranked data can only be considered ordinal. Furthermore, the affective component of pain may be weighted more heavily in adjectival scales than the sensory component, even when the sensory component is supposedly being measured.

3.6.2 Numeric rating scales

These are also easy to administer, either verbally or on paper, and are most commonly presented as ranging from 0–10, though 0–20 and 0–100 scales are also used. Some authors justify using parametric statistics with NRSs, as numbers appear equally spaced, linear and rank ordered but this is questionable, as it is unknown if the subjective feeling is equally spaced. Evidence for construct validity is good and preference over VASs has been shown by a number of authors (Downie et al., 1978; Jensen, Karoly, &

Braver, 1986). However, where several aspects of pain are being rated separately using the same type of scale, there may be a 'halo effect'; that is, patients tend to use the same preferred number to rate a sequence of dimensions. Furthermore, as some patients rate pain consistently high or low compared to others, comparisons within rather than between subjects may be more appropriate to avoid this confound.

3.6.3 Visual analogue scales

Huskisson (1974) criticised ordinal scales for their lack of sensitivity and suggested that the VAS would provide a better alternative, having been used by psychologists to measure other subjective states since the early 1900s. Offering a theoretically unlimited choice, it has been extensively tested and is deemed to have ratio scale properties, which enables parametric statistics to be used and confers superior statistical power (Price, Bush, Long, & Harkins, 1994; Price, McGrath, Rafii, & Buckingham, 1983). However, earlier findings showed that people could discriminate at most, 21 grades of thermal pain (Hardy et al., 1947) and 10 grades of ischaemic pain (Hewer & Keele, 1948); in both cases experimentally induced in controlled settings. Whilst in theory having greater sensitivity, the validity of a pain intensity scale offering unlimited choice is open to question and its use is controversial.

Some clinicians have found the VAS to be confusing for elderly people or those with severe illnesses whose ability to think abstractly may be diminished (Walsh, 1984). To address this problem, and because some patients may be unable to use paper and pen, Grossi, Borghi, & Montanari (1985) developed a coloured analogue scale consisting of a stripe shaded from dark red down to pale pink. The patient moves a slider to the point on the stripe that represents pain intensity and readings from a 100mm ruler printed on the reverse are made. This concept has been developed further to facilitate the rating of pain intensity by children. Now called the coloured analogue scale (CAS), children have found it easier to score but equivalent to a VAS (McGrath et al., 1996). It has also been tested in different adult groups. In one investigation (also reviewed in the next section), elderly people without dementia and those with early stage Alzheimer's Disease were able to comprehend it (Scherder & Bouma, 2000). However in another (Price et al., 1999), stroke patients found both a sliding analogue scale and a traditional VAS more difficult than ordinal scales for rating pain intensity.

To assist conceptual understanding, others have adapted the VAS for neurologically impaired stroke patients by using pictorial anchors to convey a range of subjective states, such as mood. Although this idea has not been applied to pain, results suggest good reliability and validity, though mostly in patients with minimal dysphasia (Arruda, Stern, & Somerville, 1999; Stern, Arruda, Hooper, Wolfner, & Morey, 1997).

3.6.4 Facial scales

Self-report measures using a sequence of facial drawings showing expressions indicating pain have been developed to assist children, and adults with deficits of language or mental incapacity, to rate levels of pain. However, there is as yet insufficient evidence to support their routine use in the field of stroke.

Children's facial scales are designed to appeal to the young, so adults could find them patronising. Their scaling varies from NRSs, VASs and VRSs, in which the lowest point or anchor represents an absence of pain, defined as zero, or 'no pain', and the highest point displays a number such as 10, or a descriptor such as 'worst pain'. The lower end of some children's scales shows a smiley face and the upper end a tearful face representing most pain; a 'neutral' face appearing somewhere near the middle (Douhit, 1990; McGrath, 1990; Wong & Baker, 1988). This arrangement reduces the number of options for rating pain and furthermore, has been shown to confound pain with affective states such as fear or unhappiness, thus potentially biasing reports of pain severity (Chambers & Craig, 1998). McGrath et al. (1990) state that their facial scale is for rating the unpleasantness or affective dimension of a child's pain and in a later study, they discriminate between pain affect and strength of pain by combining it with the CAS for rating intensity (McGrath et al., 1996).

Three published self-report facial scales have been evaluated in adults (see Figure 3, page 47). One was developed specifically for adults (Frank, Moll, & Hort, 1982) and appears to have been used to rate pain affect. One for rating intensity (Bieri, Reeve, Champion, Addicoat, & Ziegler, 1990) and another for rating affect (McGrath et al., 1996) were originally developed for children.

The earliest to be designed (Frank et al., 1982) has affectively laden anchors at each end, has been inadequately developed and does not feature in subsequent published studies. The authors compared the series of pictures with a 10-cm VAS and a five point verbal rating scale in a double blind crossover trial of two analgesics in 20 patients with osteoarthritis.

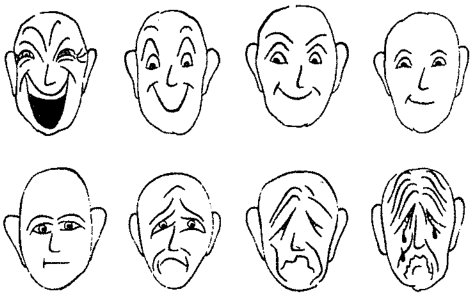
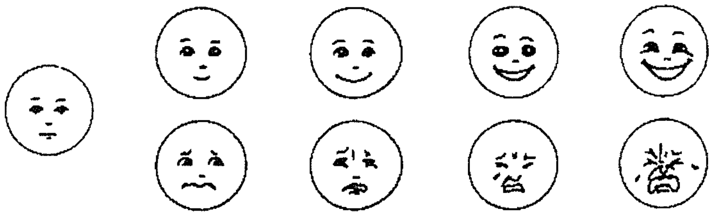
Scale name and authors (date)	Scale
a) Frank et al. (1982)	
b) Faces Pain Scale (FPS) Bieri et al. (1990)	
c) Facial Affective Scale (FAS) McGrath et al. (1996)	

Figure 3: Facial scales used for rating pain in adults.

This trial had methodological limitations. It was assumed that all three scales were measuring the same construct, despite inconsistent scaling of measures and instructions given to patients. Verbal anchors on the VAS were 'best ever' and 'worst ever' and the weekly average of scores representing pain severity in the previous 24 hours was calculated. The verbal scale (none, mild, moderate, severe and very severe) and the facial scale (Figure 3a) were rated at two-weekly intervals. Participants were asked to select the face that best represented how they felt about their pain, indicating this to be a measure of pain affect as opposed to intensity. Correlation between the scales was calculated for change in pain, but parametric statistics were used in this analysis. Although it was suggested that this facial scale could be used for adults with cognitive deficits, it has not been evaluated in this population. The authors' claim that it could be substituted for the verbal rating scale or VAS should be questioned.

In contrast, the Faces Pain Scale (FPS, Figure 3b) has been more carefully developed and validated. A series of seven expressive faces were derived from children's drawings and reflect the sequence of facial actions shown to be associated with pain. The scale achieved strong agreement on rank-ordering with re-test after one week in a group aged from six to nine years (Bieri et al., 1990). Although results suggested that the intervals were close to equal, a later study of its psychometric properties in younger children found discrimination to be weak between faces 5 and 6. Moreover, test-retest reliability was shown to be poor (Hunter, McDowell, Hennessy, & Cassey, 2000). The scale has recently been revised from seven faces to six (now the FPS-R), to align it with other scales using 0-5 or 0-10 scoring. Re-evaluation has shown that it conforms closely to a linear interval scale and is suitable for children aged four and over (Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001).

The faces that make up the FPS are less indicative of age or gender than other children's facial scales and that of Frank et al. (1982), making it more suitable for adults. It has been evaluated in older adults with and without mental incapacity (Chibnall & Tait, 2001; Scherder & Bouma, 2000; Stuppy, 1998), though this work should be repeated with the new six-point FPS-R. In a close replication of the initial study, Herr, Mobily, Kohout, & Wagenaar (1998) showed support for its content validity and test-retest reliability in a sample of adults aged 65 to 93 years, without visual, auditory or cognitive impairment. However, both construct and face validity were less clearly demonstrated as some agreed that the faces could also represent sourness, sleepiness, sadness and boredom and moreover, four said they could not use the faces to communicate pain. This highlights the need for prior explanation to ensure that patients fully understand which aspect of pain they are expected to rate; this has not always been explicit in research studies.

Two studies have evaluated facial scales in adults with cognitive impairment. Scherder & Bouma (2000) compared the FPS with the coloured analogue scale (CAS) and the FAS (Figure 3c) in three groups; one control and two with early and mid-stage Alzheimer's Disease. Patients with visual deficits, other cerebral conditions and psychiatric disorders such as depression were excluded. All were tested for comprehension of each scale by indicating how they would rate most and least pain. Following this, they were asked to point to the face on the FPS that best reflected their current pain, to the face on the FAS that matched their deep/inner feelings and to indicate their pain level on the CAS. Confusion could have occurred from the differential anchoring arrangements on the scales. Presentation of the scales was not counter-balanced, which could have biased the results, nor was there any retesting to evaluate reliability. It was revealed that only a minority of mid-stage patients understood the purpose of the FPS and FAS, showing that testing conceptual understanding is important before using facial scales in patients with cerebral pathology.

In one further study (Chibnall & Tait, 2001), an extensive set of pain ratings was made over two weeks in a group aged over 55 years without communication deficits and with no more than a moderate level of cognitive impairment. The FPS was compared with one verbal and two numeric rating scales for accuracy, reliability, construct validity, postdictive validity and bias susceptibility. It performed less well than a 21-point numeric rating box scale across all domains tested. Results cannot be generalised to other patient groups with more complex impairments and further work is necessary to see whether the results can be replicated in these patients.

3.6.5 Multi-dimensional scales

By the end of the twentieth century, clinicians were spoilt for choice in terms of available pain measures/assessments. As understanding about the complex multi-dimensional nature of pain advanced, so scales were developed to tap into these dimensions. The pendulum had swung from simple uni-dimensional scales rating intensity using a few verbal descriptors to extensive questionnaires evaluating constructs such as pain coping strategies (Rosenstiel & Keefe, 1983), beliefs about the causes of pain (Edwards et al., 1992) and its control (Skevington, 1990), pain discomfort (Jensen, Karoly, & Harris, 1991) and fear of pain (McCracken et al., 1992).

The McGill Pain Questionnaire (MPQ) is the most extensively developed multi-dimensional measure to date (Melzack, 1975). It contains 3 major classes of word descriptors, sensory, affective and evaluative; a body diagram for recording spatial distribution of pain and a verbally anchored 5-point scale for measuring present pain intensity. Following a detailed appraisal of the MPQ, Syrjala and Chapman (1984) conclude that despite impressive support for its basic structure, its reliability and its validity, there is uncertainty as to whether it can reliably show that a given clinical pain state would change after administration of analgesia. Furthermore, very sick individuals and those who are poorly educated, or whose native language is not that used in the test, have found it difficult to use.

In describing how to administer the MPQ, Melzack (1975) concedes that some verbal descriptors may be beyond the patient's vocabulary. This raises the question of their provenance. They were derived from the clinical literature relating to pain but may differ from descriptors used by people when describing their own personal experiences. De Souza & Frank (2000) conducted unstructured interviews with back pain patients and found that the descriptors they used bore only partial resemblance to those in the MPQ. These authors conclude that communication could be enhanced through a greater understanding of individuals' perceptions of pain and by allowing their experiences and insights to inform treatment. This could also apply to the development of pain assessment instruments.

Melzack (1975) also warns that data obtained from patients filling out the questionnaire themselves are sometimes unreliable, so instructions should be read aloud to ensure understanding and accurate completion. This criticism would contraindicate use of the MPQ for patients with language difficulties after stroke and furthermore, raises the issue of reliability for self-completion by stroke patients of pain questionnaires in general, since responses could be confounded if the patient has difficulty with reading or writing. Few studies describe the level of help needed or given during scale completion, but this could be of crucial importance for both validity and reliability.

3.7 Assessment of pain by proxy

It is likely that behavioural signs indicating pain have informed members of the healing professions about people's state of health since time immemorial. So it is not surprising that pain behaviours now feature as measures of pain. Proxy evaluation ranges from the descriptive reporting of behaviours witnessed in clinical situations and recorded as comments in patients' notes, to the formal systematic observation of behaviours in experimental situations. It is important to recognise the difference between these forms of proxy report. The first could include judgements of another person's pain intensity gleaned from a physical examination, which is recorded on a scale or questionnaire. This immediately introduces an additional source of error into the measurement, that of the subjective impression of the rater. In comparison, ratings of observed pain behaviours that have been operationally defined beforehand may be less subject to error, but may be rating an altogether different facet of pain. The former estimates another person's pain intensity whereas the latter rates their behaviour.

The validity of proxy ratings of pain intensity by health professionals varies. In a study comparing physicians' and patients' estimations of pain experienced during invasive procedures, physicians made accurate enough estimates about the severity of acute pain to give useful information about the likely degree of discomfort experienced, though the behaviours that informed these ratings were not described (Hodgkins, Albert, & Daltroy, 1985). Their estimates correlated well with pain rated by patients' self-report, though knowledge of the purpose of the study could have artificially increased physicians' sensitivity towards signs of pain. In contrast, trained nurses' judgements of pain behaviours observed in patients with acute and chronic pain have shown only moderate correspondence to patients self-report, but were closer for acute than chronic pain (Teske et al., 1983).

3.7.1 Assessment of pain behaviour

Only during the past three decades have observable pain behaviours been analysed in detail and used to inform the design of assessment instruments. Two broad categories feature in the literature. The earliest to be developed were scales of maladaptive pain behaviours, which have been used to advise the development of an operant-based treatment programme for patients with chronic pain syndromes (Richards et al., 1982), to assist in choosing treatment and evaluating its outcome (Keefe & Block, 1982; McDaniel et al., 1986; Vlaeyen et al., 1990) and to increase understanding of the relationship between pain behaviour and its environmental context (Cinciripini & Floreen, 1983). These are shown in Table 3 on pages 52 and 53, which also compares and contrasts behaviours and the methodologies that were used to derive them.

Table 3:
Methods used and pain behaviours derived for the purpose of designing assessments of pain in individuals with chronic pain.

First author (year)	Individuals	Methods used to determine behaviours	Pain behaviours	
Richards (1982)	Patients attending for inpatient treatment for chronic pain	Behaviours derived from a list that the authors regarded as being the most salient, reliably measurable and frequently observed	Vocal complaints: verbal Vocal complaints: non-verbal Time lying down per day Facial grimaces Standing posture	Mobility Body language Use of visible supporting aids Stationary movement Medication use
Cinciripini (1983)	Chronic pain patients with leg, back, neck, shoulder arm hand and chest pain and headache	Derived from observations during an interview asking questions about pain and performance of a physical task	Touching painful area Grimacing Gesturing Laughter	Smiles Switch to pain topic Switch from pain topic
Keefe (1984)	Patients referred for behavioural treatment for chronic low back pain	Behaviours observed during standardised physical activities divided into categories and separated into two groups	Guarding Bracing Rubbing	Grimacing Sighing
Vlaeyen (1985)	Hospitalised patients with back pain	Analysis of nursing progress notes. Low frequency behaviours omitted and descriptors pooled to generate categories	Verbal pain behaviour Non-verbal pain behaviour Fatigue Passivity Stiffness	Seeking attention Sleeplessness Anxiety Depression

Table 3: (continued)

First author (year)	Individuals	Methods used to determine behaviours	Pain behaviours	
Philips (1986)	Patients with chronic headache attending a migraine clinic	Derived from answers to questionnaires asking about characteristics of headache, personality, depression and pain behaviour	Social avoidance Housework avoidance Daily mobility avoidance Activities avoidance Daily exercise avoidance Stimulation avoidance	Non-verbal complaint Verbal complaint Self-help strategies Medication use Crying Distraction
McDaniel (1986)	Patients with rheumatoid arthritis	Developed method of Keefe and Block (1982) to include additional behaviours observed in these patients	Guarding Bracing Grimacing Sighing	Rigidity Passive rubbing Active rubbing Self-stimulation
Vlaeyen (1990)	Chronic pain patients admitted to an inpatient rehabilitation programme	Behaviours listed by nurses who observed chronic back pain patients	Distorted mobility Verbal complaints Non-verbal complaints	Nervousness Depression Day sleeping
Dekker (1993)	Patients with osteo-arthritis of the hip or knee	Developed method of Keefe and Block (1982) to include additional tasks expected to induce more behaviours	Guarding Rigidity Unloading of a joint Sighing	Rubbing Joint-flexing Stand/sit time Stand/recline time 5 metre walking time

More recently, scales rating primarily adaptive pain behaviours have been designed; that is the verbal, vocal and physical behaviours as might be seen when someone has a traumatic injury or an acute illness. Assessing generic pain behaviours of this kind is particularly important for children and adults with cognitive deficits, who could have injuries or illnesses, but who are unable to describe their pain (Breau, McGrath, Camfield, Rosmus, & Finley, 2000). These have been classified in several studies to assist the design of assessment tools for these populations. Table 4 on pages 55 and 56 lists these; contrasting the methodologies used to derive them for the purpose of assessment design and the behaviours identified.

Though there are important differences between them, the starting point for the design of all rating systems of pain behaviour has been to collect observable signs indicative of pain in the population of interest. These include both opportunistic and planned methods. Behaviours recalled from the clinical experience of specialists have been used to generate a pain scale designed for patients with chronic back pain (Richards et al., 1982) and children with multiple handicaps (Giusiano, Jimeno, Collignon, & Chau, 1995). Recall by primary caregivers has informed a checklist for rating pain in non-verbal children with neurological deficits (Breau et al., 2000; McGrath, Rosmus, Canfield, Campbell, & Hennigar, 1998), nursing home residents (Weiner, Pieper, McConnell, Martinez, & Keefe, 1996) and cognitively impaired adults (Parke, 1998).

Analysis of videotaped recordings has played a major part in the development of behavioural rating scales. The first study using this method (Keefe & Block, 1982) has been followed by others using a similar methodology, but varying some of the behaviours rated (Dekker, Tola, Aufdemkampe, & Winckers, 1993; McDaniel et al., 1986; Simons & Malabar, 1995). This method has the advantage of providing a permanent record of the actions evoking the pain behaviours and can be repeatedly watched in slow motion to evaluate reliability and to use for staff training. However, the disadvantages are that behaviours recorded in a contrived situation might not generalise to those seen in daily clinical practice and furthermore, patients' awareness of being recorded may bias the way they behave. Finally, these observed behaviours are extremely diverse and it is not always clear whether they are condition-specific or specific to the circumstances in which they have been experimentally determined.

Table 4:
Methods used and pain behaviours derived for the purpose of designing assessments of pain in cognitively impaired individuals.

First author (year)	Individuals	Methods used to determine behaviours	Pain behaviours	
Simons (1995)	Elderly non-verbal adults	Derived and adapted from the behavioural scale developed by Keefe and Block (1982); see Table 6 (page 67)	Verbal response Facial expression Body language	Physiological change Behavioural change Feedback from others Conscious state
Giusiano (1995)	Profoundly mentally impaired children with multiple handicaps	Systematic refinement of a list of items proposed by physicians specialising in the care of these individuals	Crying Painful expression Reacting to painful care Guarding of painful zone Protection of painful zone	Search of pain-easing position Pain-easing posture observed Increased tonus problems Increased involuntary movements Interest in surroundings Capacity to interact with adult
Parke (1998)	Cognitively impaired older adults	Identified pain cues from information given by knowledgeable gerontological nurses during an ethnographic survey	*Overt behaviour* Aggression Restlessness/agitation Change in daily activities *Sounds* Verbalisations Vocalisations	*Appearance* Facial expression Body language

Table 4: (Continued)

First author (year)	Individuals	Methods used to determine behaviours	Pain behaviours	
Weiner (1999)	Nursing home residents with chronic pain	Derived from structured interviews with family caregivers and nursing home staff	*Nurse caregiver cited behaviours:* Foetal positioning Increased restlessness Withdrawal Change in baseline vital signs Increased confusion, agitation Inability to eat or sleep Nausea Altered gait Tension Acting out behaviour	*Family caregiver cited* behaviours: Negative attitude Increased smoking Quieter than usual Rocking behaviour 'Obsessive-compulsive' behaviour
Breau (2000)	Non-verbal cognitively impaired children and young adults	Validation of a check-list derived from semi-structured interviews with family caregivers McGrath et al. (1998)	Vocal behaviour Eating/sleeping Social/personality Facial expression	Activity Body and limbs Physiological/physical signs
Zwakhalen (2004)	Intellectually disabled children and/or adults	Categories refined from a questionnaire incorporating 158 possible indicators of pain based on existing pain measurement scales for this population	Facial Vocal Motor Physiological	Social/emotional Injured body part Activities of daily life

Nurses' observations and descriptors from medical notes have been collated in a series of studies (Vlaeyen et al., 1990; Vlaeyen, van Eek, Groenman, & Schuerman, 1985) and finally, self-reported pain behaviours have been used to inform a checklist (Fordyce et al., 1984; Philips & Jahanshahi, 1986) and to supplement behaviours witnessed during an interview (Cinciripini & Floreen, 1983). The advantage of these methods is that they are ecologically valid and reflect what clinicians observe and might use in a clinical situation, though additional steps must be taken to determine their reliability.

Observations of pain behaviour may document departures from the normal behaviour patterns attributed to pain; they may also provide clues about affective and cognitive state. Studies approaching the problem using this pragmatic methodological approach, that of pooling individual sets of observations made in a naturalistic setting, may ultimately prove more useful in the development of clinical assessments of pain than observations made in experimental settings.

3.7.2 Facial expression

The Facial Action Coding System (FACS), developed to classify facial expressions (Ekman & Friesen, 1978), has been investigated in both laboratory studies of videotaped volunteers experiencing electric shock, cold, pressure and ischaemia (Prkachin & Craig, 1985) and clinical settings in which patients undergoing painful procedures have been videotaped (Prkachin & Mercer, 1989). These have culminated in the identification of four primary actions showing evidence of a consistent association with pain; specifically, brow lowering, tightening and closing of the eye lids, nose wrinkling and upper lip raising, and suggesting a universal facial expression of pain (Prkachin, 1992). Despite being meticulously developed and advancing knowledge in several crucial areas, for example, demonstrating the presence of pain in very young children (Craig, Prkachin, & Grunau, 1992), the judgement of facial expressions of pain may be subject to bias from stereotyped beliefs about facial attractiveness (Hadjistavropoulos, McMurtry, & Craig, 1996) or misinterpreted when pain is suppressed or faked (Poole & Craig, 1992).

There are additional difficulties with the FACS. Since extensive training is required just to gain competence in using the coding system to rate slow motion videotaped expressions, its use as an assessment tool to detect fleeting expressions in the clinical setting is impractical. Although a training programme for clinicians may improve sensitivity towards the four primary actions, as yet, this system cannot be recommended for routine clinical practice (Solomon, Prkachin, & Farewell, 1997). Finally, facial expressions may be supplemented by behaviours, such as in-drawing of breath or vocalisations, which also need to be taken into account when assessing levels of discomfort or pain, but which add a dimension that cannot be systematically rated in a study of appearance alone.

Interestingly, naturalistic observations as listed in tables 3 and 4 do not identify facial expressions of pain in terms of detailed actions. Rather these are subsumed under the generic term 'grimace' which is variously defined as, *'an obvious facial expression of pain which includes furrowed brow, narrowed eyes, tightened lips, corners of mouth pulled back and clenched teeth'* (Ahles et al., 1990; Keefe & Block, 1982; McDaniel et al., 1986), *'frowning, gritting one's teeth, biting one's lip or engaging in a facial expression which expresses discomfort, displeasure or pain'* (Cinciripini & Floreen, 1983), or which is not defined, but rated according to frequency and or severity (Richards et al., 1982). Whilst there are some similarities between these descriptors and the universal facial expression of pain, there are some variations.

Research into detectable pain behaviours is still largely at the experimental stage. Its overall purpose has been to generate better and more appropriate assessment tools applicable to people with a range of painful conditions, but to date, few have achieved recognition as fully validated clinical instruments. Reconsideration from a social perspective suggests that the process of obtaining information about pain through observing behaviours may be more complex than realised. This calls into question the validity of using refined and structured assessment tools alone to decode information about pain in populations with cognitive and communication impairments.

3.7.3 Clinical judgements of pain behaviour

In a survey of staff caring for patients in an Alzheimer's unit (Marzinski, 1991), the more highly qualified nursing staff were found to be more perceptive towards pain than nursing assistants. Some found it difficult to articulate their rationale for inferring pain in these patients, with one stating, *'you just know'*. Others were able to describe specific behaviours in greater detail, though few were common to all patients. Some behaviour was ambiguous, such that being withdrawn and quiet could be 'normal' in one individual but suggest pain in another who was usually active and vocal.

Both professional expertise in a general sense and familiarity with each individual's usual behaviour were found to play a crucial part in recognising atypical behaviours as indicative of pain, a finding endorsed in a more detailed ethnographic study of gerontological nurses' ability to detect pain (Parke, 1998). The way these nurses integrated objective scientific knowledge with intuitive knowledge involved a complex clinical reasoning process of recognising change and clustering pain cues within the context of the impaired adult's experience. A process of trial and error as well as consultation with interdisciplinary team members enabled consensus to be reached and supported the validity of nurses' inferences where the patient was unable to self-report.

3.8 Conclusion

Pain is an intangible personal experience, which has sensory, affective and evaluative qualities. When people in pain need to signal its presence to others, they use verbal and/or non-verbal means. Assessing the experience is arguably best done through self-report by the person in pain. Although evaluation of pain by proxy is also informative, it is important to differentiate between this as an estimate of another person's inner experience of pain, as compared to a measure of their outward pain behaviour. In essence, the transmission of information from the person in pain to the person who needs to know about it is a form of communication. The next chapter considers this process further from a theoretical standpoint.

Chapter 4

Theoretical models of pain communication

4.1 Chapter outline

The previous two chapters have reviewed the literature relevant to post-stroke shoulder pain from different perspectives. This one describes the theory behind the programme of research. Two related models of pain communication are introduced and the questions to be explored are established in their context. Finally, the contrasting epistemological positions of quantitative and qualitative research methodologies are discussed. It is argued that mixed methods are appropriate for the empirical studies to follow and the approaches used in these are presented.

4.2 The theoretical framework grounding the research

It is important to explain and justify the theoretical framework that grounds research. Theoretical models are useful because they present an organised representation of complex constructs in terms of their components and processes. In the human sciences they form a framework against which different conditions can be compared and contrasted. Besides, they can highlight areas where further studies are needed to fill gaps in knowledge and suggest improvements to research design. In this case, a principal aim was to discover how information about experiences of shoulder pain is exchanged between stroke patients and health professionals in order to develop better ways of assessing it. Thus, communication about pain is central to this inquiry and the theoretical basis for it can be located in two interrelated models of pain communication.

Prkachin & Craig (1995) present a model of pain communication through facial expression, which describes the experiential, encoding and decoding processes that may occur during an episode of pain (Figure 4, page 61). The model is adapted from Rosenthal's model of non-verbal communication (Rosenthal, 1982) and integrated with Ekman's neurocultural model of emotion (Ekman, 1977), the purpose being to clarify complex social interactions between people in pain and their caregivers. The model emphasises pain expression as a social behaviour serving a variety of functions, for instance, to solicit aid and warn of danger. It is also used to elicit sympathy and in the formation of interpersonal ties. It is viewed, using the metaphor of broadcasting, as a complex transactional process, whereby the individual's experience is encoded and relayed to the interpersonal world, where it may or may not be detected and decoded by an observer (Prkachin & Craig, 1995).

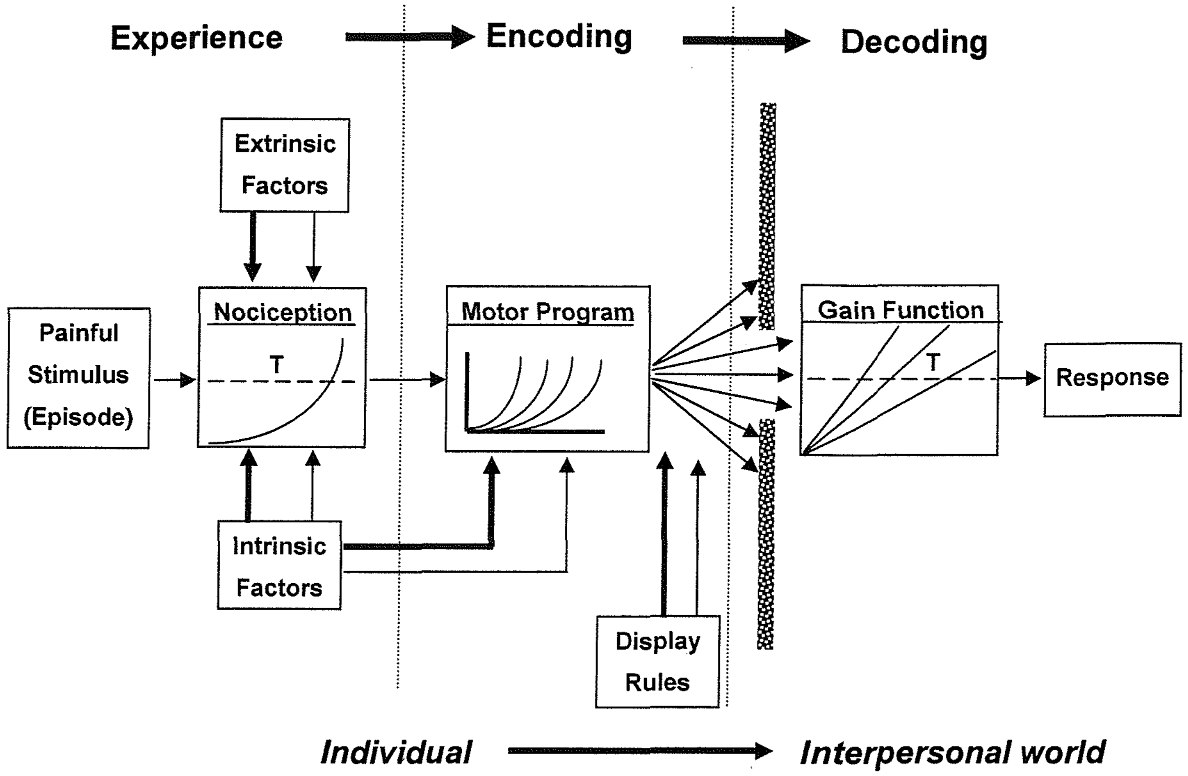


Figure 4: A Model of Pain Expression (Prkachin & Craig, 1995)
T=Threshold. Arrows with heavy lines depict amplifying influences while arrows with light lines depict attenuating influences. The patterned line represents the filter through which the display of pain passes from the individual to the interpersonal world.

4.2.1 The pain experience

As explained by gate control theory (Melzack & Wall, 1988), nociception may be amplified or attenuated by a diverse range of intrinsic factors, such as mood states or the cognitive evaluation of past experiences, and extrinsic factors, such as therapeutic interventions. Thus the experience of pain involves the whole integrated nervous system and this is clearly represented in the model. The threshold (T) represents the point at which the experience becomes evident to the outside world through behaviour. What actually triggers the crossing of the 'barrier' between nociception and behaviour is unclear, though it is thought to vary substantially between individuals.

4.2.2 Encoding pain

Pain behaviours are represented by the motor programme, which is activated when the pain experience exceeds the critical threshold. Whereas this part of the model was originally designed to explain the facial expressions which indicate pain (Prkachin, 1992; Prkachin & Mercer, 1989; Solomon et al., 1997), the same principle could be used to explain other visible postures and motor behaviours indicating pain. For example, rubbing the painful area or guarding, which are characteristic of both acute and chronic pain conditions (Breau et al., 2000; Simons & Malabar, 1995; Wilkie et al., 1992).

That intrinsic factors can affect the motor programme directly is suggested by research demonstrating an individual tendency for people to be either expressive or impassive in their facial expression of pain (Prkachin & Craig, 1995). This has implications for clinical assessment and the consequences of stroke present additional confounds. Depressed patients may become uncharacteristically impassive or emotionally labile (Kumlien & Axelsson, 2000) and moreover, anti-depressive medication can induce lethargy (Stern, 1999). From a physical point of view, paralysis can alter the appearance making interpretation of facial and other bodily expressions more difficult (Simons & Malabar, 1995).

Display rules represent the impact of sociocultural and contextual factors on expression and embrace a spectrum of influences that may, for example, lead to over-exaggeration of pain by people seeking financial compensation for injury or sympathy from the observer. This is an example of secondary gain, where an advantage may accrue from the overt display of pain. The observer's interpretation of the behaviour may be mistaken if they have been deceived by behaviours such as these (Poole & Craig, 1992). On the other hand, masking of the expression may occur if people wish to conceal the fact that they are in pain in a public situation. Little is known about the extent to which pain concealment occurs in hospitalised patients.

Development of Prkachin and Craig's (1995) model to widen the perspective of the central encoding component is shown in Figure 5, page 63. This model divides expressive behaviour into verbal and non-verbal programmes and highlights the significance of message clarity and observer bias on decoding the expression of pain

(Hadjistavropoulos & Craig, 2002). The term 'verbal programmes' refers to expressive pain behaviour that is controlled by higher mental processes, such as self-reported pain whereas 'non-verbal programmes' refer to behaviour that is less subject to voluntary control and is understood mainly through observation, for example facial expression.

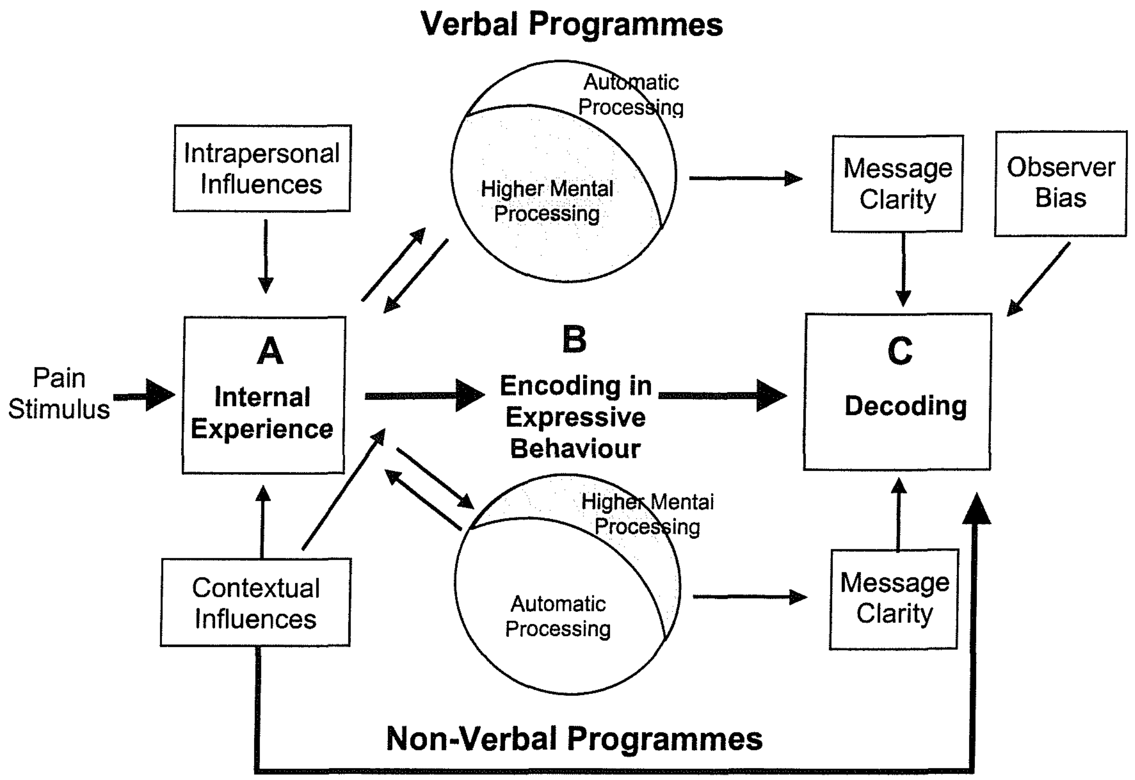


Figure 5: The Communication Model of Pain (Hadjistavropoulos & Craig, 2002)
The pain stimulus is modulated in internal experience (A) by intrapersonal and contextual factors. This is encoded in (B) in self-report and non-verbal, behavioural expression, as a product of various automatic and higher mental processing programs. Observers decode cues (C) with varying success, reflecting attention and response biases.

There are advantages and disadvantages to both these behavioural mediums. Although pain behaviours dependent on higher mental processes might be thought to reveal more accurate information about the experience of pain, they may be subject to more purposeful distortion than automatic behaviours. On the other hand, the interpretation or decoding of automatic behaviours may be more difficult (Hadjistavropoulos & Craig, 2002). As the higher mental processing capability of stroke patients is variable, the relative weighting given to self-report as compared to observed behaviours will differ across patients and needs to be carefully judged when assessing pain.

4.2.3 Decoding pain

The filter between encoding and decoding in Prkachin and Craig's (1995) model represents the broadcasting of pain to the interpersonal world and defines whether the message goes out and is received. The significance that the display of pain holds for the observer/respondent forms a crucial part of the transaction and three elements are described. Firstly, detecting and discriminating the available information, secondly, attaching meaning to it and thirdly, reacting to it in an appropriate way. These three elements may be misconceived in a variety of ways but providing the pain display has been perceived and interpreted, the likely outcome is a behavioural response on the part of the observer, who may act to provide relief or comfort. The potential for pain behaviours to elicit such a response may have evolutionary origins because of their adaptive value in promoting survival (Hadjistavropoulos & Craig, 2002).

4.2.4 Detecting and discriminating information

In general, inferences about pain are made from consideration of verbal and vocal expressions, non-vocal behaviour, such as guarding or stiffness and physiological activity, for instance sweating or increased respiration. However, where people have limited communication and/or understanding, detection and discrimination may be more complex. From the perspective of stroke, detection may fail because of a loss of information transfer, which could be due as much to circumstances as to the characteristics of individuals. For example, health care settings are often short staffed and clinicians may be preoccupied with a range of organisational problems (Weiner, Peterson, & Keefe, 1999). Prioritising according to clinical needs in the early days after stroke may favour stabilising patients' medical condition and addressing competing problems, such as incontinence, feeding and general immobility. This can limit interpersonal communication and the building of therapeutic relationships (Jones, O'Neill, Waterman, & Webb, 1997).

Sensitivity, knowledge and experience are crucial to information transfer. For example, this may fail if the decoder is not aware that the individual in pain is aphasic (Blomqvist & Hallberg, 1999). As pain behaviours may occur more frequently while the patient is involved in structured activities (Anderson et al., 1987; Jensen, Bradley, & Linton, 1989), the opportunity to observe them while helping with everyday tasks, such as dressing or washing is greater than when the patient is sitting still. However, if the helper is unable to see their face, detection may again fail. Simple sensitivities to ways of promoting information transfer by adjusting the environment are essential to obtaining credible indications of pain. For example, sitting near the patient in a well lit area to gain attention and ensuring that spectacles and hearing aids, if worn, are used (Partridge, 1994).

4.2.5 Attaching meaning to the pain display

'Gain function' refers to the importance placed on the display of pain by the observer, which is mediated by their personality and clinical or personal knowledge. Systematic biases can occur, for example, if the pain display is perceived as attention seeking and deliberately ignored. There may be striking individual differences in judgements of pain by others, with some observers showing a steep 'gain function', being more likely to report pain on the basis of minimal evidence and others having a gradual 'gain function', requiring more information before concluding that someone is in pain. Significant inter-individual differences were demonstrated in a study of carers in nursing home residents with chronic pain and a range of cognitive impairments. This revealed poor agreement between nurses and family caregivers of pain behaviours and pain intensity (Weiner et al., 1999). Desensitisation to pain and nurses' preoccupation with other patient management problems were suggested as possible explanations. This concurs with earlier findings that clinical experience with pain patients may increase the tendency to underestimate pain (Prkachin & Craig, 1995).

4.2.6 Reacting appropriately

Appropriate reactions are again dependent on the knowledge and experience of the decoder in the context of the painful experience recognised. Little is known of how much different groups of health professionals know about post-stroke shoulder pain and how they attend to and react to patients who lead them to believe that they have pain.

4.2.7 Applying the theoretical framework to stroke

In summary, both these models of pain communication provide a useful theoretical background for this research. They have been logically constructed from theories of pain, pain behaviour and communication. Each stage has been informed by research across a range of painful conditions. As generic models, they offer a conceptual framework for investigating more specific conditions. By exploring each stage of pain communication from the experience of pain to its detection by another person, which has not been done before in the context of post-stroke shoulder pain, this thesis will make an original contribution to knowledge.

4.3 Methodological approaches

Philosophical assumptions about the nature of reality influence the epistemological position that a researcher adopts when seeking knowledge. This, in turn, drives the selection of methods and forms of analysis most appropriate for a specific research question. Examination of the literature has revealed that studies of post-stroke shoulder pain, as well as much research into pain and its measurement in general, have been designed according to the principles of traditional western scientific thinking; that is using hypothetico-deductive, or quantitative, methods. The epistemological position adopted here is positivism, which in its most radical form assumes that a value free objective reality exists and that continued investigation, using consistent, accurate methods of measurement, will ultimately piece together the facts of the matter and reveal its true nature.

In quantitative human research, information from a sample of individuals is used to make some inference about the wider population of interest; thus the sample acts as a proxy for the population (Altman, 1991). Research designs can broadly be divided into two categories. In observational studies, descriptive data is collected either prospectively or retrospectively and is counted, but not manipulated, by the researcher. Examples include surveys or case control studies, which may be cross-sectional; that is observations are made once only, or longitudinal, where serial observations are made to investigate change over time. Alternatively, experimental studies comprise those in which an intervention is tested to determine its usefulness in clinical conditions. In this instance, the researcher manipulates the study design to test a predetermined hypothesis, as is done in randomised controlled trials when investigating the efficacy of a new treatment.

The advantages of quantitative medical research lie in its major contribution to epidemiology, diagnostics and pharmacology. Its credibility depends on attention to detail with respect to sampling, data collection, measurement and statistical interpretation. Large statistically representative (preferably random) samples are required to establish population parameters, reference ranges and causal relationships between variables of interest, in order to generate accurate predictions about the population as a whole. To minimise bias, objectively defined data, free from sources of error, must be collected and critically, the instruments chosen to measure variables of interest must be both reliable and valid. Without attention to these issues generalisations cannot be made, therefore it is the responsibility of the researcher to control the conduct of the research in a standardised and replicable way.

This draws attention to a limitation of the positivist approach, as constraints may be placed on participants and variables of interest through exclusion of any that do not fit the prescribed criteria of a tightly regulated scientific investigation. Criticism can be fairly levelled at selective studies into heterogeneous conditions like stroke if in drawing conclusions, generalisability of findings has been wrongly assumed. A further limitation of quantitative research is that ephemeral subjective phenomena, for instance, emotional states, are far less easily measured than more stable, discernible variables, such as muscle strength. From an epistemological standpoint, critics have challenged the view that objectively defined data represent a form of reality on the grounds that researchers themselves select and influence both the data to be collected and its context. In doing so, they unavoidably become involved in the construction of reality through their interaction with research participants, and neither can remain value-free (Murray & Chamberlain, 1999).

Despite these limitations, quantitative methods have made a substantial contribution to current knowledge about pain. Discovery of the physiological mechanisms of the central and peripheral nervous systems and the systematic testing of analgesic medication would not have occurred without the combined efforts of research teams world wide using such methods (Hardy et al., 1952; Melzack & Wall, 1988). Unfortunately, despite elucidating some aspects of post-stroke shoulder pain, this paradigm has so far failed to determine its causes and associations. Rather, these are still widely debated by professionals, who remain uncertain about the true nature of this problem.

Returning to the autobiographical extracts at the end of Chapter 2, a different way of representing the reality of post-stroke shoulder pain can be seen. Though brief, these qualitative accounts are rich and contextualised. By giving us a glimpse of some of the emotions that accompany pain in naturalistic settings, they convey something of its complex, multi-faceted, individual nature. Also highlighted is the discontinuity between these patients' recognition of pain and its perceived detection by hospital staff. This point is taken further at the end of Chapter 3, though from a different perspective; that of nurses who, in caring for mentally impaired adults, described using a process of clustering pain cues within the context of patients' experiences to gain a better understanding of it. What these accounts have in common is their insightful descriptions of experiences of pain and the complex social interactions that underpin assessment. They illustrate the reality of pain from a phenomenological perspective, add a dimension of understanding missing from the medical literature and reveal the potential benefits to be gained by further exploration of the problem of post-stroke shoulder pain from this alternative position.

The study of phenomena in naturalistic settings using qualitative methods is founded on an ideographic paradigm; that is it discerns the world from the individual's point of view, capturing experiences that cannot be quantified. The scope of qualitative inquiry crosses many different disciplines, embracing a spectrum of traditions and methodological approaches developed within a complex historical field. The definition suggested by Denzin and Lincoln (1998) summarises its fundamental principles:

> 'Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them' (Denzin & Lincoln, 1998)

This epistemological position sees reality as socially constructed through the interaction between individuals and their interpretation of events. The aim here is not to measure the characteristics of large groups but instead, to develop coherent, perceptive descriptions of individual similarities and differences and thus to provide an additional route to understanding the essence of complex situations. Qualitative research welcomes diversity and allows a research question to be examined from different viewpoints. The researcher does not control the research agenda in the same way as for quantitative research. Rather than gathering data according to an objectively measured and structured pre-ordained sequence, he or she takes on the role of observer, facilitator and interpreter, remaining open to new insights which shape both the direction and explication of the inquiry.

The limitations of qualitative inquiry lie in the localised origin of its findings; that is claims cannot necessarily be made about the wider population, nor can predictions be made about future cases. As Willig (2001c) points out, qualitative research tends to be holistic and explanatory rather than reductionist and predictive. However, such limitations should not undermine the worth of this approach as a means of adding to knowledge, after all the validity of generalisation can also be questioned in some quantitative studies. Instead, this should be acknowledged and accepted as a difference of emphasis.

In the positivist arena of health research, qualitative researchers have had to work hard to convince sceptics of the credibility of their findings. Whereas those adopting a quantitative approach can be explicit about scientific rigour and the ways in which subjectivity and measurement bias are countered, researchers using an inductive approach celebrate subjectivity for the insights it brings, and actively seek to explore processes and meanings that cannot be quantitatively measured. Mays & Pope (2000) argue that though these differences are believed by some to preclude use of the same criteria for judging findings, nevertheless the rigour of the two approaches can be verified according to two broad criteria: Validity and relevance. However, these must be operationalised differently to take account of the differences in the goals of research.

The difficulty of establishing validity in qualitative research is well documented (Denzin & Lincoln, 1998). From an historical perspective, the concept of validity has evolved in tandem with development of the multiple methodologies and research practices that characterise this paradigm. The concepts of reliability (stability of findings) and validity (truthfulness of findings) as applied to positivist research have been tried, tested, reformulated and tried again in an interpretative context, but found wanting. This has led to the realisation that different qualitative methods advocate different evaluative criteria and there is no easy solution that fits all (Whittemore, Chase, & Mandle, 2001).

At the risk of over-simplifying a complex problem, it can be argued that the pragmatic way through this maze of suggested techniques to maximise validity is to ensure that a detailed, transparent and reflexive report of the research procedure is made available for scrutiny. The interplay between the researcher and the researched shapes the conduct and interpretation of the entire process of research, so declaring and dealing with this as a potential source of bias is an essential means of affirming authenticity. Particular attention must be paid to any prior personal interests and attitudes held by the researcher that could influence the interpretative process (Flick, 1998a; Mays & Pope, 1995).

It is also crucial to be able to justify the method chosen to answer the research question. The rationale for decisions made about sampling, methods of data collection and analysis should be made explicit. Barbour (2001) cautions against using these procedures prescriptively but instead recommends that each should be carefully considered and embedded, not only in the research design most appropriate to the question being investigated but also when presenting and interpreting the findings. To inform the research report, the value of keeping narrative field notes as a structured way of recording practical issues, personal experiences and reflections during the course of a study cannot be overestimated. As Coffey (1999) points out, this process involves us in the construction and production of textual representations of a social reality of which we are a part.

The relevance of a qualitative study is established through its contribution to knowledge, as judged by the confidence with which findings are endorsed by others in the field, and from its perceived application to other (similar) circumstances (Mays & Pope, 2000). However, there is a more fundamental form of relevance that cannot be determined from analysis of, say interview transcripts alone. This is the relevance that comes from developing new insights that significantly advance understanding of the issue under investigation. As maintained by Coffey & Atkinson (1996), theorising is integral to analysis in good research and the full implications of analysis should take the researcher beyond the manipulation of the data to develop new ideas about the field of research.

Differences in the philosophical traditions described above are often expressed in terms of their extreme positions, thus biomedical and social perspectives are sometimes seen as opposite ends of a spectrum and incompatible with each other. However, there is no logical reason to regard them as mutually exclusive, since the long view of scientific discovery shows that the flow of evolving knowledge encompasses both qualitative and quantitative components. Pope & Mays (1995) argue that in health services research, particularly where conditions are poorly understood, qualitative description can be an important prerequisite of good quantitative research. Such instances are to be found in the development of pain assessment measures. In recognising the limitations of regarding pain as a specific sensory quality varying only in intensity, Melzack (1975) derived the McGill Pain Questionnaire from qualitative descriptors of pain before testing it quantitatively. Similarly, scales of pain behaviour have been derived from the subjective accounts of caregivers (McGrath et al., 1998), nurses (Parke, 1998) and physicians (Giusiano et al., 1995).

Whereas the starting point of a quantitative study can be a hypothesis derived from an experiential account, a qualitative study more usually arises from the absence of a coherent factual explanation for a problem; that is, it is used to fill gaps in a framework of understanding. But the relationship between the two paradigms can be more closely woven than this. A quantitative investigation into the causes of a medical condition complemented by a qualitative investigation of how individuals make sense of it is likely to lead to a more comprehensive understanding of illness behaviour than would be discovered from either method alone (Smith, 1996). Moreover, it is now believed that integrating qualitative findings with quantitative data can usefully inform the development of clinical guidelines (Kelson et al., 1999) and that knowledge of both participant and professional perspectives gained from qualitative research can play an important part in the success of randomised clinical trials (MRC, 2003). When integrated within the same systematic review, this approach can also identify complementary ways of improving interventions and their implementation (Thomas et al., 2004). Biomedical and social paradigms can therefore have a symbiotic relationship, blending with and drawing from each other. Indeed, it is argued, the use of mixed methods to research complex social interactions, such as pain and its communication, has distinct advantages.

4.4 The research agenda

As mentioned in section 4.2.7 (pages 65-66), three stages of pain communication represented in complementary theoretical models informed the studies that were carried out here; each one exploring a different stage. This broad approach was adopted because there is a need to establish how shoulder pain ought to be assessed, as well as to explore better ways of assessing it. At present, interaction about shoulder pain in clinical situations, and the choice of instruments used to rate it more formally, appears to be based on the assumptions of health professionals founded on research using a narrow biomedical approach. Little attention has been given to the multi-dimensional nature of pain, nor to the diversity of the stroke population in terms of their capacity to receive and convey information about pain. The need to inform improvements in practice required investigation of several different lines of research that, taken together, offer multiple perspectives on shoulder pain assessment in stroke patients.

Accordingly, the first two studies positioned the assessment of post-stroke shoulder pain as a form of social behaviour and used inductive approaches to investigate it from the perspective of patients (the experience) and health professionals (decoding the experience) in natural settings. The third study took a different but interrelated position. Assessing aspects of someone's pain for the purpose of, say, determining the efficacy of a new treatment, entails obtaining information about it in a standardised way (encoding the experience). Pain rating scales are the tools that promote this kind of information transfer between a patient and an assessor. To address the need for more accessible rating scales for stroke patients unable to use existing ones, a new scale was designed and tested using quantitative methods.

4.4.1 Experiences of shoulder pain and its expression

Finding out about the experience of post-stroke shoulder pain and the intrinsic and extrinsic factors that stroke patients believe to influence it was the starting point, since knowledge of these factors is limited. In contrast, a substantial body of research of this kind has been instrumental to understanding other common conditions, such as back pain, and moreover, has informed a range of assessment instruments that tap into the many psychosocial and contextual variables that influence pain. These have been shown to assist in managing such conditions more effectively (see section 3.7.1, pages 51-53).

The aims of the first study were twofold. Firstly, to gain a better understanding of the shoulder pain experiences that mattered most to stroke patients in the naturalistic context of hospital settings. Secondly, to find out how they perceived communication about these experiences to occur between themselves and members of the multi-disciplinary team. A focus group methodology was used for this purpose and was analysed using an interpretative phenomenological approach.

4.4.2 The health professional's perspective

As there was little understanding of how health professionals in hospital settings acquire information about shoulder pain from stroke patients, the second study investigated this aspect. Particular emphasis was given to identifying the behavioural signs that alert staff to the presence of shoulder pain, as being of most importance for patients with communication and cognitive deficits who are unable to report on pain themselves.

Again, this study was carried out with a view to informing the development of better ways of assessing shoulder pain in these patients and thus to enhance the quality of their care. A critical incident methodology was used to identify the discrete pain behaviours observed by staff that could be used to inform such an assessment. This is represented theoretically by the 'motor programme' (see Figure 4, page 61) that encodes pain in an expressive form that can be decoded by another person. The decoding process that staff use is also of critical significance to pain assessment as it determines how well they are able to verify the presence and severity of pain in patients with communication deficits. This study also enabled this process to be explored in some detail.

4.4.3 Development of a tool to facilitate self-report

The assessment of post-stroke shoulder pain is complicated by the heterogeneous nature of stroke. Some patients remain articulate and rational; they are able to understand and express information about pain as well as anyone else. Others, however, lose the capacity to do this entirely. Spreading along a continuum between these two extremes are patients who retain variable levels of comprehension and variable degrees of receptive and/or expressive language use.

The reviewed literature highlighted the lack of suitable self-report instruments for patients whose higher mental processing ability had been affected by stroke. This was also identified as a problem during development of the ICP for managing post-stroke shoulder pain that preceded and influenced this work (see Chapter 1, page 3). The capacity for expressing information about pain not only varies widely between patients but also within the same patient over the time course of recovery. Thus it is essential that options for pain assessment should include a flexible range of different instruments that capitalise on the strengths of individual patients in order to give as many of them as possible the autonomy to self-report on pain. Taking this argument one step further, Gramling and Elliott (1992) maintain that a comprehensive pain assessment should combine practical measures of both overt behavioural and subjective aspects of pain, since taking these multiple parameters into account enhances the evaluation of interventions for pain. Thus to complement the study that explored the detection of behavioural signs of pain, and to address the acknowledged gap in accessible self-report instruments, a pictorial scale for rating subjective pain intensity, designed with the needs of stroke patients in mind, was developed and evaluated using quantitative methods.

In summary, mixed methods were used to research the three interrelated parts of pain communication; the experience, its detection and a novel way of facilitating transmission of information about it. By viewing pain assessment from multiple perspectives in this way, it is argued that a more comprehensive understanding of the complexity of the subject will be gained. The following chapters present each of the three studies in turn and elaborate further on relevant methodological issues where appropriate.

Chapter 5

Stroke patients' experiences of shoulder pain

5.1 Chapter outline

The first qualitative study is described in this chapter. After stating its purpose, the issue of subjectivity as a potential source of bias in qualitative research is addressed. The advantages and disadvantages of using a focus group methodology to find out about stroke patients' experiences of shoulder pain are discussed and this is followed by an introduction to the interpretative method used for the analysis.

The methods section incorporates a more specific account of the procedure and the process by which the data was analysed. The composition of the groups is considered in advance of a detailed analysis of the findings. Lastly, the study design and findings are discussed.

5.2 Introduction

Most of the literature on post-stroke shoulder pain is written from the perspective of health professionals, both practising clinicians and researchers. The experiences of patients have hardly been explored. Thus the purpose of this study was to uncover stroke patients' experiences of shoulder pain, to find out what they think and believe about it and to gain an understanding of their perceptions of pain communication in hospital settings.

5.3 Reflections on subjectivity

This study marks a departure from the traditional western scientific approach that grounds most research in the field of stroke. The aim here is for the researcher to enter the world of stroke patients and to represent their construal of shoulder pain in order to enrich clinicians' understanding. In these circumstances, it is essential for researchers to reflect on their background, experiences and attitudes, as these things shape their way of seeing and interpreting the world around them and must be acknowledged when undertaking qualitative research. This is the nature of subjectivity. To make these reflections transparent, and to draw attention to the close personal interaction between the researcher and the participants, the first person will be used at times from here on.

Because subjectivity is, in the main, an unconscious part of one's make-up, Peshkin (1988) argues that researchers should seek it out not retrospectively, but while research is actively in progress. He describes how he recorded his thoughts and feelings at different stages of his research and how this enlightened him to a number of discretely characterised 'identities', which represented different aspects of himself, and which emerged differentially according to his circumstances at any one time. Keeping field notes during the planning of this study enabled me to reflect on the way my understanding developed and furthermore, to consider the effect that my subjectivity might have on the interpretation of findings. I found myself thinking about the study at all sorts of times and committed these thoughts to paper as they occurred, ending up with a series of scraps which I kept in a file. These 'textual memories' (Coffey, 1999) were supplemented with more detailed field notes made during the process of data collection; extracts are integrated with the text of this chapter. This process enabled me, like Peshkin (1988), to become conscious of my multiple identities.

Firstly, I have an identity as a health professional; an expert accustomed to seeing stroke patients as recipients of my specialist knowledge and care. My initial training as a physiotherapist had required an understanding of 'normal' physical functioning as a benchmark against which to assess abnormality and thereafter, to devise a treatment programme, based on physical interventions, to redress or compensate for any identified deficits. For some time, my professional practice in the field of neurological rehabilitation had continued to be based on this 'biomedical model' of care; as a member of this scientific community, I had therefore shared in its ideology. Though I knew that the 'biopsychosocial model' of care was increasingly influencing rehabilitation professionals and their practice, I had nevertheless spent many years considering post-stroke shoulder pain specifically from a physical perspective. I realised that I would now have to suspend my preconceived notions about its causes, and the way I imagined staff responded to it, in order to reflect accurately what patients believed and felt about it. I wondered whether patients in my study would criticise their care and if so, whether I would feel the need to defend my fellow professionals.

From the perspective of my more recently assumed identity as a researcher, I have become aware of the many ways in which innovative ideas are being tested and implemented to improve patient care. A multi-disciplinary team approach to rehabilitation is now widely accepted (Langton Hewer, 1994), holistic interventions are being developed (Wade & de Jong, 2000) and qualitative studies investigating psychosocial aspects of health appear in leading medical and rehabilitation journals (Parry, 2003). I was enthusiastic about the thought that I could contribute to this new body of knowledge. However, in the world of medical research, there are many that still adhere to the quantitative approach and they could be sceptical of my findings. I was mindful of the responsibility I had assumed as the self-styled intermediary between the patients in this study and the wider research world and this evoked feelings of uncertainty. I wondered if this concern would bias the way I interpreted and wrote about my findings.

Like most people, I have experienced pain in my lifetime ranging from mild to severe; comprehensible to inexplicable. I have also been a patient in hospital on several occasions and can still remember the feelings of distress and apprehension that accompanied some of these experiences. As an ordinary human being, I am able to feel a sense of empathy towards my patients. But should I, indeed could I, set aside memories of my pain and my instinct to empathise with others in pain? Empathy has been described as the ability to enter into and understand the world of another person and to communicate this understanding to him or her (Egan, 1986). But as Holliday (2002) points out, qualitative researchers must regard themselves as outsiders looking in and take on the discipline of making the familiar strange, which runs counter to the natural instinct of seeking familiarity with another person's suffering. Yet again, empathy can occur at a cognitive level or progress more deeply to an affective and a physical level (Ellingson, 1998). Although my interpretation of what patients said could be influenced by my imaginings of how I might have felt in their place, I realised that I would need to draw on my professional training to keep feelings of empathy at a cognitive level and any emotional response in check.

Finally, I felt a sense of responsibility for asking patients to give me their time. Although the purpose of this research study was to add to knowledge, it would not necessarily benefit these people. I had a personal interest in it, since it would contribute to my academic development. I wanted the patients who agreed to participate to feel positive about the experience and even to enjoy it. I knew I would feel ill at ease if I thought they regarded their participation as distressing, boring or a waste of time. I realised that these uncertainties could influence the way I behaved and reacted in the group situation.

In sum, I had identified the need to set aside judgements about how I expected patients to think and feel, to take on the role of an impartial outsider and to adopt a non-prescriptive approach in encouraging groups of stroke patients to tell of their experiences. I needed to enable them to construct their world of having shoulder pain for me to interpret as best I could, but taking my preconceptions into account. In other words, I realised I would be adopting an ideology that was very different from that which I had espoused before, and that I would have to position myself differently to do justice to this study.

5.4 Rationale for the study design

A focus group methodology was used for this study, though consideration had been given to using semi-structured one-to-one interviews as an alternative. There are similarities and differences, advantages and disadvantages to these approaches. Each one is amenable to the same sampling strategies, allows participants to talk about their experiences in their own words with guidance from the researcher and presents the opportunity to explore a topic in depth. Both methods therefore lend themselves to gathering accounts of people's experiences of, and beliefs about, health and health care. Essential differences between them centre on researcher-participant dynamics, the influence of privacy on disclosure and group interaction as a source of new insights.

While semi-structured interviews provide the opportunity for in-depth conversations and allow each interviewee to take 'centre stage', the researcher and the questions asked have a tendency to 'drive' the interview, which can constrain participants' freedom to reflect on wider issues (Reed & Roskell Payton, 1997; Willig, 2001b). Then again, Smith (1997) maintains that, while taking the form of a conversation, a semi-structured interview is usually a fairly one-sided conversation. These limitations may be overcome in a group discussion, where the main interaction is between participants and where the researcher should play a more passive role (Bender & Ewbank, 1994). As the balance of power is weighted towards the participants, the attitudes of the researcher are less likely to intrude, helping to maintain his or her position as an outsider.

On the other hand, group interaction can have a detrimental effect not found in a one-to-one situation, since the contributions made by its members can be limited by personal inhibitions, the social niceties of turn taking in conversation or by 'competition' between participants. This is more likely if some are more confident or more articulate than others and are inclined to dominate the discussion, in which case, there could be a tendency for conformity towards the views of more assertive participants. However, this is less likely if they are describing their personal experiences and feelings about them, as distinct from being asked to venture opinions on a public issue, such as spending on health. Then again, Kitzinger (1995) has claimed that although group discussions have been found to generate more critical comments than interviews, in her experience, some residents in an elderly care setting tried to prevent others in a focus group from criticising staff because they felt it was wrong to complain.

Some people may feel more comfortable discussing personal issues in a private interview but on the other hand, others could feel more exposed. There does not appear to be a hard and fast rule for determining which method is best for which individuals, as diverse variables, such as their personality and the nature of the topic under discussion, may affect their preferences. It has, though, been suggested that group interaction can be more spontaneous (Sim & Snell, 1996). It can also encourage people to explore common experiences in ways that would be less easily uncovered in a one-to-one interview, lead them to disclose previously unarticulated thoughts and reveal convergence of views (Kitzinger, 1995). Moreover, some researchers with experience of both methods have found that participants are more willing to discuss private experiences of a harrowing nature in the presence of others sharing the same difficulties. They believe the richness of data gathered in this way is greater than that obtainable from one-to-one interviews because group interaction can take the conversation in unpredicted directions and yield new insights (Fielding & Thomas (2001).

There is no specific evidence to suggest that this finding necessarily applies to patients with neurological conditions. Nonetheless, the dynamics of a group may stimulate people in general to recall incidents they might otherwise have forgotten about when others are discussing similar events, which may be of particular relevance to stroke patients recovering from a stressful and confusing experience in a hospital setting. Moreover, in a study exploring patient and carer views of stroke rehabilitation, Kelson et al. (1999) used both focus groups and individual interviews. In discussing their findings, they do not differentiate between methods in terms of the richness of the data they obtained. However, they do maintain that a benefit of group discussion is that patients with expressive language difficulties, who are often excluded from research studies, may be empowered to contribute by agreement or dissent with views expressed, though they may find it difficult to articulate such views themselves.

These contradictory issues do not preclude using focus groups as a means of obtaining data, but it is important for researchers to recognise them (Sim, 1998). On balance, I decided that the advantages of using focus groups for this study outweighed the disadvantages.

5.5 Rationale for the analytical framework

The method chosen for analysing qualitative data should be grounded in a theoretical position that reflects the philosophical origin of the research question. In the last chapter, pain communication was described in theoretical terms as a complex social interaction, so questions about this could have been posed and investigated from a number of perspectives. For example, social constructionism takes the position that reality is constructed from the meanings that individuals ascribe to events occurring in social situations and is interested in exploring how people develop a shared understanding in these circumstances. Thus the nature of the interaction between patients and health professionals, for example during a clinical assessment of pain, would have been an interesting question to explore. Had this been the case, a form of sequential analysis could have been used to elucidate the way that conversations about pain proceeded and to find out how patients interacted with professionals in this everyday situation, as is the aim in conversation analysis. Discourse analysis presents another option that could have been used to uncover how the meaning of social reality for patients in pain is formed through the language they use to describe their experiences to others (Flick, 1998b). Both these approaches would shed light on important aspects of shoulder pain and its assessment.

However, much of our knowledge about the phenomenon of post-stroke shoulder pain derives from assumptions made by health professionals; virtually nothing is known of the patient's perspective, so there were compelling reasons for focusing on their viewpoint, both in methodological and analytical terms, as a means of redressing this imbalance. Moreover, it is evident from pain theory (see section 3.3.3, pages 39-40) that the individual's inner experience of nociception and the cognitive and emotional variables that influence it precedes communication about pain, making this a logical starting point. For these reasons, interpretative phenomenological analysis (IPA), an approach based on social cognition theory was chosen to explore patients' private experiences of pain and their beliefs about its communication.

IPA was introduced to mainstream health psychology in answer to the need for an analytical method that could uncover how individuals make sense of their ill health; that is what they think and believe about it (Smith, 1996). This is particularly suited to health psychology research as it can help to explain a person's health related behaviour. In this case, it offered a valuable method for gaining a better understanding of patients' experiences of pain as well as their perceptions of communication about it. IPA is premised on participants being invited to tell of their experiences in their own words, and on the ability of the analyst to distil the essence of these experiences and to reveal their meanings for participants. A basic tenet is that the researcher's own conceptions are an integral part of making sense of another person's personal world. Thus the analytic account can be said to be the joint product of the reflection by both participant and researcher (Smith, Flowers, & Osborn, 1997).

IPA involves a defined sequence of steps which have been meticulously described in the context of studies investigating the psychological experiences of people with a variety of medical conditions (Osborn & Smith, 1998; Smith et al., 1997; Smith, Jarman, & Osborn, 1999; Willig, 2001a). Simply put, analysis begins with a systematic search for themes. Summary comments, associations and preliminary interpretations are noted in one column of the transcript and another is used to note emerging theme titles which are ultimately clustered to form concepts. These are synthesised to generate superordinate themes. An ideographic approach may be used to examine one transcript in intense detail and to produce a preliminary coding scheme before incorporating other transcripts and adjusting themes according to their significance as the process continues. In this way, the analysis follows a cyclical course. An alternative approach involves broader coding with preliminary grouping of themes from the first transcript. New transcripts are then coded afresh and clusters of themes identified from the pooled data (Smith et al., 1999). Whichever method is favoured, re-visiting the transcripts throughout is vital to ensure that the findings are true to the source data.

This highlights a limitation of the method, in that conversations, particularly when held in a group setting, do not necessarily follow a logical sequence of question and answer but shift from topic to topic, digressing and returning to issues that participants see to be important at intervals throughout. They may contradict themselves and each other, so their thoughts and beliefs are not necessarily made transparent within the transcripts and the researcher must become intensively involved with the text, not only to reveal these issues, but also to ensure that they genuinely reflect participants' perspectives in a balanced way. This is demanding of both time and effort and for this reason, only small numbers of participants are recommended if IPA is to be used successfully. As Smith et al. (1997) point out, this may limit the generalisability of findings.

Although semi-structured interviews are typically used to generate data for this kind of analysis, IPA has been used with texts created in other ways. However, applying IPA to focus groups has theoretical implications arising from the influence that group dynamics can have on the interpretative process. Reed & Roskell Payton (1997) point out that though focus groups are sometimes chosen as a research method precisely because of the benefits that group interaction can have on generating data, these benefits are not always evident in the approaches to analysis and the reporting of findings. They go on to highlight the pitfalls of clustering themes out of context, which can result in the dynamics of group processes becoming lost. They also stress the crucial importance of immersion in the raw transcripts to enable exploration of conversational sequences, so that insights that are developed within the groups can be thoroughly interpreted. Further facets of group interactions that are worthy of analysis include the use of humour and the exchange of anecdotes, which can enhance understanding of people's knowledge and attitudes (Kitzinger, 1994).

A literature search of studies published since IPA was introduced in 1996 revealed one that had used focus groups alone (Dunne & Quayle, 2001) and another, which had combined focus groups with semi-structured interviews (Flowers & Knussen, 2001). Both investigated health issues. In the former study, group interaction was not considered in the analysis and as Kitzinger (1994) puts it, '*It was hard to believe that* *there was ever more than one person in the room at the same time.'* In the latter, however, the analysis of conversational exchanges illustrated the depth and complexity of the issues being discussed and demonstrated how debates occurred during the group session. Awareness of these issues was clearly an important requirement for the successful use of IPA with focus groups.

5.6 Method

5.6.1 Sampling strategy

As compared to random sampling, a numerically based method of selection generally used in quantitative research, purposive sampling is used in qualitative research and seeks to recruit individuals with the characteristics critical to understanding the phenomenon of interest. The context, the nature of the population of interest and participant relationships all influence sampling (Boyatzis, 1998).

5.6.2 Study context

Patients cared for in hospital are in the best position to describe communication about diverse experiences of pain with a range of health professionals, as incidents associated with pain are likely to be fresh in their minds and they are also likely to have regular contact with different members of the multi-disciplinary team. Thus in-patients, identified by hospital staff as having shoulder pain, were the target sample. I chose to conduct the study in the hospital where I had worked before beginning my academic course, and where I was still employed. Although I was well known to some members of staff on the RRU, my visits there had been infrequent in the months leading up to the study and the current population of patients would not have known me. The hospital has a Stroke Unit that I have not had any involvement with, which caters for patients over the age of 65. Patients are admitted to both settings from acute medical wards and in the case of the RRU, many come from other hospitals within the region, which spans several counties. This was significant because it meant that most group participants would have been cared for in at least one other setting and would therefore be able to share experiences from different perspectives.

5.6.3 Participant sample

Confidence to participate in discussion with others increases when there is homogeneity between members of a group (Sim & Snell, 1996). In this case, participants would be homogenous to the extent of having had a stroke and having shoulder pain. However, because there is heterogeneity within the stroke population, and because the aim of the study was to explore the diversity of hospitalised patients' experiences of shoulder pain and its communication, further limitations to sampling would have been disadvantageous. There were, though, some constraints, as the capacity to participate in a group interview was clearly essential and this in itself meant excluding patients who were bed-bound, those unable to understand English, or whose treating clinicians considered their speech and language deficits to be too severe for meaningful participation. Patients with behavioural impairments likely to disrupt a group were also deemed unsuitable. These restrictions limited the pool of potential participants in hospital at any fixed time. Groups were therefore convened once a sufficient number of patients meeting the study criteria had been identified by their therapists as willing to participate.

Opportunistic sample selection such as this has its disadvantages, in that participants may not represent the full range of individuals with the condition of interest, which could limit the validity of the findings. However, it may be the only feasible method of gathering patients meeting specific criteria in some health care settings (Bender & Ewbank, 1994). To maximise the diversity of participants in each group and to reduce the effect that pre-existing interaction between them could have on group dynamics, it was proposed that each group would include patients drawn from both the Stroke Unit and the RRU. Furthermore, it was proposed to convene several groups, which extended the scope for including a variety of patients. Maximal variation sampling might have been attained had the study been extended to alternative settings and this is accepted as a limitation of the approach.

5.6.4 Ethical issues

Ethical approval was sought and granted by the Harrow Research Ethics Committee (Appendix A) and the Southampton University Psychology Department Research Ethics Committee. I agreed to comply with research governance regulations. Had any patients been identified as at risk of harm, it would have been my responsibility to report this as required by my professional code of conduct. My main ethical concern was the issue of confidentiality. I was aware that there would be no absolute safeguards to prevent patients from divulging, for example, accounts of poor care to others outside the group.

Post-stroke shoulder pain is not a particularly sensitive topic but naming/shaming staff and other hospitals could be. I hoped that stressing the importance of confidentiality to the group participants would curb the chance of this happening.

5.6.5 Planning the groups

Setting up each group was time consuming. At the outset I had no prior affiliation with the Stroke Unit, but arranged to meet the Nurse Manager and the Stroke Liaison Research Nurse to explain the study. They were both helpful and supportive. They communicated with other staff on my behalf and agreed to help with identifying potential participants. Liaising with staff on the RRU was easier because I was familiar with the routine and could regularly ask staff I knew about the patients.

Researchers using focus groups to elicit views about health issues vary in their citation of optimum group size. This appears to derive from their own and others' experiences of 'what works best'. Kelson et al. (1998) set a guideline of four to eight people for their series of groups exploring patient and carer views of stroke rehabilitation, which agrees with Kitzinger's (1995) recommendation. In contrast, Bender & Ewbank (1994) describe groups of up to twenty being common in developing countries where turning potential participants away may cause offence. However, they point out that small groups of four or five maximise contributions from each participant and that this is likely to be an advantage where the aim is to explore a narrowly defined topic in depth, as was intended in this study. While it is unusual to convene a focus group with fewer than four participants, there is no evidence that three people interacting with each other are any less likely than four to generate rich insights into a health issue of importance to all. Indeed, Cronin (2001) points out that three may be a suitable number if the topic to be discussed is a sensitive one and Morris (2001) found that joint interviews with couples can enable them to create shared meanings as they speak, thus adding an extra dimension not obtainable in individual interviews. It is argued that the key to a successful focus group lies in the quality and richness of the interaction between participants, which depends as much on the personalities of those taking part and the skill of the facilitator in guiding the conversation as the precise number of individuals involved.

I was uncertain as to how many eligible patients would be available at any one time. However, the plan was that once four or more suitable patients had been identified, their therapists would ask them if they would be willing to meet me to discuss what was entailed. It is usual to conduct a series of groups to ensure that the topic under discussion is comprehensively aired and the plan was to review the findings after the third group to determine whether new data was continuing to emerge. Ultimately, sixteen patients participated in four groups, by which time the discussion was covering similar ground. Two groups were held with four patients in each and two others with three and five patients respectively.

I arranged a time to explain the study to each patient, introducing myself as a research physiotherapist connected with the hospital, but not directly involved in patient care. I also explained that a nurse in a similar position would assist me. On the one hand, this could have been advantageous, in that patients would regard us as trustworthy professionals with an understanding of their predicament but on the other, it could have inhibited them from being critical of their care in the hospital because of our affiliation with hospital staff.

I gave each patient an information sheet (Appendix B) and suggested they might like to discuss the study with relatives before deciding whether to agree to participate. The importance of confidentiality was stressed on the information sheet and reiterated at the beginning of each group. I made it clear that we would like to tape record the conversation, but that patients would not be identifiable in the analysis. After allowing time for them to consider this, we met again to explore possible days/times for the group. Once a consensus had been reached, confirmatory letters were written to patients and respective unit staff were informed.

The groups were held in the early evening. There were two reasons for this; one being so that patients would not miss daytime ward rounds or therapy sessions. I also thought that after supper, which was generally served between 5.30 and 6.30, patients might enjoy the opportunity for a social gathering and feel more relaxed than at other times of the day. Because the venue can influence the mood of a group and their ability to relax, the Day Room on the Stroke Unit was chosen as it was spacious, newly decorated and appropriately furnished.

The room was booked and details recorded in the communication books on both wards. On the day of each group, I saw each patient again to make sure they were still happy to participate and to obtain their signed consent (Appendix C). A notice was pinned on the Day Room door to make sure no one would interrupt the group. The seating was arranged, refreshments organised and the audio recording equipment was checked.

5.6.6 Facilitation

Two focus group facilitators are advisable for both practical and theoretical reasons. One can concentrate on taking the lead, leaving the other to be on hand in case of difficulties; for example, should problems arise with the recording equipment or members wish to leave the group for any reason. In addition, since 'two heads are better than one' one facilitator may have insights that the other missed and prompt deeper exploration of an issue through probing. Afterwards, a second person can act as a sounding board when considering modifications to the topic guide for future groups, and in affirming or contesting the findings.

The groups were run by myself and Rosemary, a colleague working as a facilitator in the audit department, but with a nursing background. We had both attended the same training course on running focus groups, and she had previously run a number of groups investigating patient satisfaction with different aspects of health care provision. We met several times to discuss the topic guide that I had drafted and to agree who would deal with 'housekeeping issues', organise the introductions and start the conversation off. When assuring members that we would use pseudonyms and not reveal any identifying information to others when reporting on the findings, we also asked them to respect each other's confidentiality and not to discuss what had been said outside the group.

5.6.7 Topic guide

The topic guide (Appendix D) included open questions chosen to encourage patients to talk freely about their experiences of pain. The guide formed the starting point for the question trail but was not followed in a rigid way and evolved as successive groups were held. The opening question was a direct invitation for participants to talk about the starting point of their pain: *'When did you first realise that your shoulder was painful?'* It was reasoned that this information would be easy for individuals to recall, but that experiences would vary across the group and that comparing them would 'get the ball rolling'. Subsequent questions raised issues about the impact of pain, other people's awareness of it and communication about it. Probes were used to ask more explicit questions if participants were hesitant in their responses. I had paper and pencil ready to make notes if the need arose.

At the end of the topic guide, I had listed some questions about using pain scales. To facilitate any discussion that might occur on this subject, I had prepared a series of cards with common pain intensity scales on. I was interested to find out what meaning they had for these patients. Along with them were samples of a newly designed pictorial pain intensity scale (described further in Chapter 7). Introducing material of this kind is a recognised strategy for focus groups (Kitzinger, 1995).

5.6.8 Reflections on facilitation

Because I suspected that inadequate care contributed to shoulder pain but knew that the scientific evidence to support this was scarce, I rather hoped that patients would reveal this as a problem. The temptation to concentrate on this as a specific topic at the expense of other equally pertinent issues could have biased the process of facilitation and led to an unbalanced analysis. We discussed the need to steer clear of asking leading questions about poor care, or giving our opinions about issues raised. We did, however, realise the importance of encouraging patients to elaborate on their recounted experiences where they were relevant to the purpose of the study.

Having taken part in several 'mock focus groups' as part of the training course I had been on, I remembered the irritation of failing to make a point I wanted to because one course participant acting as facilitator had fired questions out at every pause. Both Rosemary and I were mindful of the need to be sensitive to quieter participants who might want to get a word in, whilst also respecting their possible wish to be silent. We knew that participants should be guided towards an interactive discussion among themselves and that we as facilitators should 'hold back', but we also wanted to enable each patient to feel comfortable with the idea of sharing their feelings about pain and its communication. We were therefore ready to step in and invite the more passive individuals to comment on an issue if it seemed appropriate.

5.7 Managing the data

5.7.1 Transcribing the recordings

Each group was tape-recorded and transcribed verbatim shortly after it had taken place while still fresh in my memory. Even so, it was a difficult exercise as on occasions patients' speech was barely audible. Four came from ethnic minority groups and had strongly accented voices. Others had quiet voices and there were two with dysarthria who had slurred speech. There were also interruptions and some cross talk, which made it hard to identify murmurs of assent or dissent made by others in the group at the same time as someone was speaking.

I gave pseudonyms to patients and my co-facilitator, choosing names that reflected their age, gender and ethnic group, so preserving their identities while retaining confidentiality. Though the transcribed text was an almost perfect record of the conversations as they occurred, the emotion behind the words, inflections in speech, facial expressions and body movements could not be adequately represented. To re-live these extra dimensions while analysing the data, I listened to the tapes again as a separate exercise, both before and after the systematic analysis.

I added punctuation to the transcribed text if this clarified its meaning. Interruptions, unfinished speech and speech that was omitted in extracts were indicated by ...... Square brackets were used to indicate laughter or murmurs of assent while a patient was speaking and to indicate where substitution for names or places had occurred to maintain anonymity, such as [Ward]. The extracts reproduced in the analysis section are referenced by group number, page number and line. For example, 3.5.18-22 refers to focus group 3, page 5, lines 18 to 22. Italics are used in extracts to distinguish facilitators' speech from that of patients.

5.7.2 Analysis

In discussing the issue of validity when using IPA, Osborn & Smith (1998) stress the importance of internal coherence and presentation of evidence; that is the need to demonstrate a consistent interpretation of the findings that is justified by the data and extensively supported by verbatim evidence from participants. To this end, it is recommended that a second person should independently review some of the transcripts, and that both analysts should agree on theme categories before the analysis proceeds further. The aim here is to ensure that the emergent account is verifiable from the data, albeit that there may be more than one way of finally interpreting it.

I decided to describe each group separately to draw attention to differences before beginning the main analysis. An ideographic approach to IPA was then used, whereby themes were generated from intensive involvement with the transcript of the first focus group followed by the remaining three. Rosemary and I independently coded the first transcript and shared our findings, discussing issues that we had perceived differently. Group dynamics were closely considered in that preliminary coding highlighted patients' agreements, disagreements and the comparisons they made with one another, as well as their views, beliefs and feelings. In due course, when extracts were clustered under thematic headings, chunks of conversation were given equal prominence to individual accounts, so that the way patients interacted to affirm, refute or expand on each others' experiences could be explored in the context of the findings.

5.8 Results

5.8.1 Composition of the groups

Four groups were held comprising a total of 16 patients; ten were recruited from the RRU and six from the Stroke Unit. There were six women and ten men, whose ages ranged from 36 to 81 (median 58.5; IQR 50.5 – 73) years. The length of time between onset of stroke and participation in the groups ranged from three to 60 (median 15.5; IQR 10 – 24.5) weeks; thus as well as recounting specific incidents, patients were able to convey how their understanding and feelings had changed over time. Between them, they had experienced care in 19 different wards/units/hospitals.

All but one group member had left-sided hemiplegia and all had severe paralysis of the affected arm with functional loss. Although three retained intact sensory appreciation, the rest had profound sensory impairments (that is, somatic sensory and/or proprioceptive loss). All confirmed that they had a painful shoulder at the time of recruitment, but the precise nature of their pain was not investigated through formal assessment. They were all able to communicate reasonably fluently, though some were hesitant in their speech. While several had cognitive deficits and/or mood disorders these were not so severe that they prevented active participation in the discussions. All patients were asked how they wanted to be addressed in advance of meeting together.

All but one chose to be called by their first name. Sessions lasted for between one and one and a half hours.

5.8.2 Differences between the groups

Group 1

The four patients in the first group were all forthcoming and did not require guiding or restraining. Louise was the most talkative and became emotional at times when recalling some of the things that had happened to her. Although her contributions took up time, she did not force her views on others or inhibit them from introducing their own experiences. Though Claire was as disabled as Louise, had also had an awful time and at 52 was around the same age, she appeared to be more detached, but at the same time extremely perceptive. Chris, the youngest at 41, seemed self-assured and appreciative of his care. He was less critical than the two women were, possibly because his experiences of care had been generally better than theirs. Peter, the oldest at 81, was also remarkably accepting. He introduced humour to the group and lightened the discussion when it had become rather heavy. I realised that a long series of reported incidents about pain could potentially be rather depressing for others to listen to, and that the personalities and attitudes of its members could powerfully influence the overall mood of a group.

Group 2

Three patients took part. This group was less equally balanced than the first, though all three members expressed strong feelings. Edward and Nita were both over 70 and less than three months post-stroke at the time the group was held. Edward appeared to be emotionally labile but though upset at times, he always regained his composure quickly. Nita's mood appeared to be low; she was resentful and bemused by some of the things that had happened to her. In contrast, Trevor at 55 was more than a year post-stroke and was much more talkative with a great sense of humour. Although he tended to dominate the conversation, his optimistic attitude had a positive effect on the overall atmosphere of the group. He reflected on a range of previous experiences with the benefit of hindsight. These insights were interesting for Edward and Nita to listen to and served to stimulate responses from them.

I was interested to see if their responses would confirm some of the points made by the first group, so had slightly modified the topic guide before convening this one. We placed the fourth theme (impact of pain) after the first (self-awareness of pain) so as to try and draw out patients' feelings about their pain and how significant it was in the context of their other problems. Even so, this group was harder to facilitate than group 1; we did more prompting and asked more questions. This time I passed round the pain scales to stimulate comments about formally rating pain and this was a successful adjunct to the experiences volunteered by the group members.

Group 3

This group was the hardest of the series. Four patients took part, but they were less expressive and less able to volunteer their thoughts than those in the previous two groups were. Martin and Maria were both over 70 whereas Adrian and Victoria were both under 40, although this division of ages had less impact on the flow of conversation than patients' cognitive and speech impairments. Martin had problems with memory, attention, concentration and problem solving. Though Maria had no cognitive problems and expressed her feelings very well, she was the oldest at 79 and quickly felt fatigued. She left the group early on so she could go to bed. Both Victoria and Adrian behaved as if they had a low mood. Adrian was also emotionally labile, had some difficulties with comprehension and contributed least of all to the group. This may have been partly because he was free of pain by the time it was convened. Victoria was the most talkative but the hardest to understand as she was dysarthric and had a strong ethnic accent. This may have been an additional impediment to the flow of conversation within the group.

To get the discussion going I asked more questions than before and felt uncomfortable about the fact that I was directing the conversation more than I had wished to. On the other hand, had I not done this, the patients might not have relaxed into the conversation that did ensue. Nevertheless, they contributed some interesting insights and appeared to value the opportunity to share their experiences with others undergoing the same life changes; indeed Victoria said she had thought beforehand that she was unique in having shoulder pain. Again, the pain scales were useful as a prompt to further discussion.

Group 4

This group was much more successful than the previous two, despite the fact that two patients had multiple complex problems. Ralph, the youngest at 50, had cognitive communication difficulties, problems with memory and concentration and a history of depression and self-harm. Jill had a lively and uninhibited manner but also had problems with memory, concentration, depression and emotional lability. However, these difficulties did not prevent them from articulating their experiences and feelings fluently. Along with Paul, who was the least physically disabled out of all the group members, they made the strongest contribution to the discussion and furthermore, indulged in occasional high spirited banter which lightened the mood of the group, though unfortunately on one occasion, it drowned out one of the quieter members.

Charlie, the eldest at 81, was rather deaf and had less of a shoulder pain problem than the others. Though some of the discussion passed him by, he was still an active contributor. Mr. Bikas was quietly spoken and tended to wait until he was addressed directly before volunteering his views. He was the one participant across all four groups who at times, struggled to make his voice heard over the other more vociferous members in the group. It is suspected that deeper insights might have been obtained from a one-to-one interview with him.

5.8.3 Reflections on analysis of the findings

My initial analysis of the first transcript was a broad overview. The themes I picked out first had come to mind as being essential points to use when presenting the findings to hospital staff. There was evidence of good and bad practice, which could be used to educate staff in improving care. Rosemary came up with similar themes. At this stage, we were approaching the data from a 'biomedical model perspective'. However, on re-reading the transcript in line with the recommended IPA method I became more deeply involved in the text and was fascinated by the themes that began to emerge. From a new perspective, I began to see myself as a third dimension in the pain communication model, reflecting on and interacting with patients' experiences of pain so that I, in turn, could broadcast information about pain, but in a different direction and for a different reason. Not because I needed help or attention from my interpersonal world, but because I wanted to draw attention to the difficulties patients had told me about and contribute towards changing their care for the better in the wider world.

I was tempted to select the most eloquent extracts to support the findings. However, this would have meant that a few patients were cited much more than others. I gave careful consideration to groups of extracts where the essence of their meaning reflected a common theme. Sometimes I chose an extract, albeit less well expressed than others, to reflect the diverse characteristics of the participants, to convey the difficulty that some had in articulating their experiences and to enable them all to be represented.

5.8.4 Findings

Though individual experiences were diverse and complex in nature, some similarities were evident from the accounts patients gave. Coding of transcripts and the subsequent pooling of extracts sharing the same codes generated an underlying classification of interconnected themes. Emerging from this analysis was a portrayal of shoulder pain and communication about it, as an evolving phenomenon. To begin with, this entailed discovery from two perspectives. Firstly, patients discovered their pain in the context of the physical changes that had taken place in their bodies after stroke. Secondly, in the context of their dependency, they perceived differences in the awareness of, and responsiveness to pain shown by the staff caring for them. This blend of intrinsic and extrinsic factors evoked each individual's emotional response to pain, as well as shaping their understanding and interpretation of it.

Patients used this new found knowledge to take responsibility for their predicament to a greater or lesser extent. Again this occurred in two ways; mainly by trying to become self-reliant, which revealed itself through the strategies they devised to obtain relief and to solve problems causing pain. But in addition, as experts in their condition, some were empowered to participate in dialogue with the professionals caring for them about the nature of their pain, their specific needs and the best ways of meeting them. Where successfully achieved, this served the purpose of informing the care they received and of educating staff about the nature of post-stroke shoulder pain and ways to manage it.

5.8.5 Superordinate themes

To reflect this portrayal of post-stroke shoulder pain as it emerged from the analysis, the process from discovery to taking responsibility was divided into four main themes: Detecting a changed body, perceiving care, developing self-reliance and informing professionals. Table 5 (page 95) lists these, together with their associated sub-themes.

Two of these sub-themes, feelings and communication, were shared between all four main themes but are included under those with which they were most strongly associated.

Table 5:
Classification of themes

Discovery → *Taking responsibility*

1.0 Detecting a changed body	*2.0 Perceiving care*	*3.0 Developing self-reliance*	*4.0 Informing professionals*
1.1 Loss of control	**2.1 Haphazard**	**3.1 Recognising needs**	**4.1 Expertise**
1.1.1 Tangled body	2.1.1 Carelessness	3.1.1 Self-preservation	4.1.1 Knowledge of self
1.1.2 Disconnected arm	2.1.2 Ignorance	3.1.2 Learning from experience	4.1.2 Multi-disciplinary team
	2.1.3 Conflict		
1.2 Evolving sensations		**3.2 Determination**	**4.2 Changing roles**
1.2.1 Sensory confusion	**2.2 Responsive**	3.2.1 Struggle for independence	4.2.1 Conflict
1.2.2 Interpreting pain	2.2.1 Comforting	3.2.2 Problem solving	4.2.2 Patient as teacher
	2.2.2 Belief in therapy		
1.3 Feelings			
1.3.1 Frustration	**2.3 Communication**		
1.3.2 Suffering	2.3.1 Threshold		
1.3.3 Anger/resentment	2.3.2 Assumptions		
1.3.4 Depression			
	2.4 Feelings		
	2.4.1 Fear		
	2.4.2 Distrust		
	2.4.3 Gratitude		

5.8.6 Stage 1: Discovery

5.8.6.1 Detecting a changed body

Although this main theme is sub-divided into issues concerning physical dependency, sensory awareness and emotions, in reality these were inextricably linked. This section presents a series of extracts that reflect how patients' awareness of change came to light, what these changes felt like and what they thought about them.

Patients became aware that they had lost control over their body immediately after their stroke and their consequent dependency was seen as a significant cause of frustration and discomfort. The context of dependency was frequently the starting point for the more specific accounts patients gave about losing control of the upper limb. For example, Trevor described his body in bed as being 'beached like a whale' and his arm in this situation as becoming 'tied in a knot' when he unsuccessfully tried to turn over. Maria discovered how the loss of control over her body during the night contributed to generalised pain and stiffness:

> ***Maria*** I find that when they put you to bed and then you slide down, they put you up in a sitting position but you slide down, and then you in an awkward position and you lie down, and then it's very painful. In the morning you completely stiff, not only the shoulder but the neck and the good shoulder as well. 3.5.18-22

Distortions of the body schema, in which the arm was perceived as disconnected from the rest of the body, were common. Patients across all four groups recounted surreal scenarios where they lost their arm without realising it and were later unable to find it. It seemed that their encounters with these unpredictable events enabled them to become familiar with their changed body and discover the implications of these changes for everyday functioning. Once an awareness of pain had recovered, it sometimes served as a warning system by prompting a search for this 'lost' part of them. Trevor described how the worst pains were the ones that caught him unawares at night and in the following extract, tells of his struggle to locate his arm. It was evident from the other two participants' wry laughter that this was a familiar experience; indeed Edward had alluded to a similar incident earlier during the discussion. This example shows how Trevor, the raconteur of the group, tended to act as spokesman for the others, who listened intently, agreeing with much of what he said.

> ***Trevor*** … you know, it would be arm or shoulder was giving you the, had woken you up and er, trying to find your arm you know, trying to find it with your good arm to pick it up and reposition it because you can't move it and er, you know, without having proper sensation I mean, there's been times when I've, you know, looked at my hand and, is it mine at all?
>
> ***Edward, Nita*** [laughter]

> ***Trevor*** Who does it belong to? I gather by that chuckle you know exactly what I mean. So, you know you're lying there, you're uncomfortable, you know it's got something to do with this shoulder and arm but you go to pick it up or move it and you haven't got a clue what you've got hold of. Is it yours at all ...... ?
>
> ***Edward*** Mm, mm. 2.11.14-26

As conveyed by Trevor, a sense of the arm's alienation from the body was commonly described, as was the failure to recognise ownership of the arm when visual cues were absent and a feeling that it belonged to someone else. Personification of the arm was revealed by several patients, who talked to the arm, and about it, as if it was a separate entity needing to be controlled:

> ***Ralph*** ..... my arm is not interested in obeying me at all. 4.7.33-34

Paradoxically, some patients lacked perception of body movement when it occurred, but then perceived it when none existed. Peter recounted an episode in which he watched in fascination as his bowl of porridge started to move across the table. He looked around to see if a nurse was removing it but there was no one there. Only then did he realise that his arm had dropped over the side of his chair causing him to fall sideways (1.18.23-32). In contrast, he experienced phantom movements of his paralysed arm and found their lack of realness disappointing. His introduction of this topic resulted in two other members of the group sharing similar experiences:

> ***Peter*** I'm pointing to the gentleman over there as far as I'm concerned. I'm pointing my hand at you, but it's down here. But I've got the feeling that it's there. 1.20.8-10 ...... It's a great disappointment when you find it's still lying on the cushion. 1.20.15-16

Becoming aware of the sensory changes that contributed to dependency and making sense of peculiar sensations in the arm did not always occur instantly, but evolved over a variable length of time. Terms such as, 'useless', 'dead' and 'like frozen meat' were used to describe how the arm felt early on, which was the antithesis of the way the rest of their living body felt. Experimentation and introspection played a prominent part in learning about sensory changes. Several patients told how they touched or pinched themselves to see what they could and could not sense. Others were acutely aware of the significance of temperature and were curious to find out if members of their respective groups suffered the same unpleasant feelings. For some, the affected side of the body could seem excessively hot, whereas others described coldness as a disagreeable phenomenon. Louise described a peculiar experience, which she found puzzling and continued to brood over when no explanation was forthcoming from her therapist:

> ***Louise*** But a very funny thing, a little experience is anything metal touched with my arm give me such a funny sensation like a shock like when you get like a, er, an electric something, like a shock you know you get. ... It's very funny, I don't know, so I tried it. The first time I experienced that is when I had a one of my container, like my deodorant container. I just put it round to hold it and I had this sensation. Then I tried a spoon or fork on my arm and I had this really sharp sensation like a shock. I asked physio before what does it mean? She say she couldn't tell me what it's all about. ... But this thing, I'm still, I'm still trying to figure out why metal gives me that kind of shock sensation. It's very, it's not very nice feeling. It's very funny. 1.22.10-31

Maria described her recovery of upper limb feeling as the arm suddenly 'waking up'. This brought with it an awareness of pain; an experience echoed by others. With the benefit of hindsight, both Trevor and Claire believed that their perception of pain had been 'masked' for a period after their stroke, and that this had been to their detriment. Claire was resentful of the fact that she had not been better protected from the possibility of harm by those looking after her:

> ***Claire*** I, when I first had my stroke which is now, what seven months ago, I was totally unaware. I had no sensation at all in my left side, and um, I didn't know when I was knocking my shoulder about. I would um, be in a manual wheelchair and reach over the back to get things with my right arm, and be actually getting my left shoulder blade caught against the handle of the chair. And, just didn't realise what part of me was blocking my, you know, why I couldn't reach further round. And, when I actually began to get sensation back um, my shoulder became very painful and I think it was because I'd been allowed to do so much hauling around while it was actually not telling you, you know, I wasn't getting the message that there was pain there. 1.1.20-29

With recovering awareness, patients learnt to understand the relationship between loss of control over their body and the persistence of pain. Even so, this knowledge did not prevent repeated accidents and they remained vulnerable to harm for quite some time.

It seemed that the cognitive appraisal of risk and the perceptual awareness of its reality remained separated.

> ***Chris*** Um, yes, I forgot it quite a lot and it was always, you know, hanging down there if I forgot to pick it up quick before I was going through a door or, and jammed it in between the chair and the door, I sort of nearly broke my fingers once. 1.9.13-16

Much of what was described during the groups indicated that patients engaged in this process of sensory self-discovery by themselves, though in a few cases they only realised the extent of their loss while being tested by clinical staff. Within this theme of 'detecting a changed body', the main role of clinicians appeared to be as informer; to offer a rationale for pain. This enabled patients to gain further insight into the complexity of their predicament:

> ***Paul*** I accept that it [the pain] was caused by, not the stroke itself, but my efforts to overcome the stroke. Um, but I was trying to er, compensate when I walked, for the fact that um, my right leg was affected by the stroke. And in so doing, I was imposing um an extra burden on the shoulder muscles. Um, that's what I have been told by the professionals. 4.1.20-24

Despite being aware of pain, group members found it extremely difficult to put their nociceptive experiences into words, especially where sensory loss persisted. Claire, who had a combination of central and local pain, said she was initially confused and unable to recognise her problem. She was only able to separate out allodynia, where a normal stimulus such as touch is perceived as painful, from pain that was specifically located within the shoulder, some weeks after her stroke:

> ***Claire*** I was quite confused because I actually had pain all down my left side which I hadn't been able to discriminate, between shoulder pain and, you know, specific shoulder pain and just the general pain and that had sort of come on over a period of time and I hadn't really sort of recognised that I was in such pain, and I was then put on some tablets which reduced the, the receptors, basically from recognising it as pain and um, that was fantastic. I was really sort of happy because I felt so much better and then I was able to recognise, you know, which pain was actually the shoulder and um, notice when it was helping which was with movement. 1.3.18-27

In general, patients tended to portray pain in terms of its intensity and in relation to the circumstances evoking it; rarely describing its qualities, though the use of simile was common. Pain felt internally appeared to be associated with a malaligned shoulder joint, and was described as occurring when their arm had dropped off the arm support, if it remained unsupported during walking or at night. It frequently resolved as soon as the arm was re-positioned:

> ***Chris*** It's extremely difficult to describe pain. The arm, the shoulder felt as if that was out of position um, really it was like a deep pain. It wasn't a muscular surface pain. It just felt deep in the bone. 1.4.9-11
>
> ***Martin*** Well it's some sort of nagging pain you know as if somebody's hammering you from within. ..... And it persists. It's a persistent pain. Doesn't stop. 3.10.12-15

Several patients only experienced transient pain on movement, either while being challenged during physiotherapy treatment or because someone had pulled their arm. In these situations it was often 'sharp' or 'stabbing'. Others mentioned situations such as leaning forward onto the arm or inadvertently rolling on to it at night as being 'agonising' and 'horrible'. Stiffness and tightness, either associated with prolonged immobility or increased muscle tone, also caused intense suffering. Louise described the distress she endured while having physiotherapy for her hypertonic, contracted arm, and her sense of being disempowered from exerting any control over it:

> ***Louise*** I'm in terrible pain with that now, in spinning pain, because we do a lot this afternoon to get the arm straight but it would not stay straight, so they told me I have to keep it in one position. 1.14.36-38 ..... It's so tight that you think that somebody's put super glue on and glue you and when you touch it you feel you have to wrench it because it's so tight there, it won't move. 1.15.2-4

Learning to identify and manage feelings about pain was an important component running through the process of detecting a changed body. Although the emotional impact of becoming dependent after a stroke and of the pain as a supplementary problem were closely linked, it was clear that patients were additionally distressed by their painful experiences. It was frustrating being disturbed during sleep. Waking up with a painful, twisted arm and a hand that was 'clawed like a bird' (1.2.37) was miserable and demoralising. Being hurt when the arm was wrongly positioned or unsupported during walking was an unwelcome distraction from being able to concentrate on the task in hand. Patients were insightful about the link between pain and various mood states, such as anxiety:

> ***Mr. Bikas*** Worry, worry about something..... Yes, it brings me the pain, severe pain. Well my worst pain is only when, when I'm worried about something. 4.30.8-17

Feelings of anger were common, being associated with pain under different circumstances. Adrian felt angry when he was in pain, whereas Trevor described feeling angry in anticipation of pain if his occupational therapist wanted to practise dressing with him when he would have preferred to be left in peace. Victoria suppressed the anger she felt when she experienced pain on trying to move her arm and found that her religious belief helped her to cope with it:

> ***Victoria*** It make me angry but I can't hit anybody, I can't yell at anybody so I just tell God. My arm, this here is only hurting, that's the only part that's hurting. I don't know the name of this, though I know that where my shoulder blade was when it moves up and down your back, that was hurting very bad, like somebody hit a rock there. 3.3.4-10

Louise, who was severely affected by her problems, identified the vicious circle between pain, depression and anger:

> ***Louise*** The pain make me feel depressed. The more depressed I get, the more angry I will get with myself, the pain will increase 1.15.18-20

A broader belief about the psychosocial impact of shoulder pain was revealed in a conversation between two patients. This interchange exemplified the way in which group interactions generated new and unexpected insights. In answer to a question asking whether patients thought that having a painful shoulder had specifically affected their progress, Jill agreed that it had and went on to express the unfairness of this extra burden. This feeling was endorsed by Paul and prompted him to describe its further effect on his enjoyment of a social life. He perceived this misery as extending beyond himself to impact on others in his social circle.

> ***Jill*** Well because um, we're all learning to walk and do things again that we've, we've all done probably for fifty odd years and all of a sudden we can't. So life is very difficult as it is and having this pain, you know, you've only got to move your arm or your shoulder in a certain way, or sometimes you just turned in the odd way and you're in a lot of pain as well. It just does not seem fair.
>
> ***Paul*** Yeah
>
> ***Jill*** Mind you, nothing's fair at the moment. But to have that on top of everything else, plus the fact it's another thing for the physios and that to try and help us with.
>
> ***Diana*** *Mm. So how does that make you feel?*
>
> ***Jill*** Why? Why have we got to have that as well as? 4.12.25-36
>
> ***Paul*** I mean its also er, a nuisance socially. We need a few week-ends off. 4.13.1 ...... When you go to, or you can't go to a restaurant unless they've got the right arms on the chair, the chair, the they can, that your arms can rest on and that you know, you have a place you can sit comfortably you're, you know, it's um, it's very very, it's very very difficult to fit in and if, er you, er and you're constantly aware that you're probably, um bit of a killjoy sometimes. 4.13.3-7

Because this analysis has distilled multiple experiences of pain into a single report, it paints a bleak picture; indeed for these patients it clearly was a miserable and unwelcome extra problem to contend with. However, despite all they had gone through, and were continuing to go through, a sense of acceptance of their changed bodies, of hope and determination for the future prevailed for many of them. Some had a marvellous sense of humour and used this when recalling some of the bizarre events they had experienced. There was an exchange of repartee at times during three out of the four group sessions. Patients laughed at each other's accounts of losing the arm, at the difficulty of going to the toilet whilst simultaneously keeping guard over the arm, at the strange positions therapists expected them to maintain, and at being frustrated by the impossibility of scratching an itch that couldn't be reached by the unaffected hand. One patient had obtained a back scratcher and his group agreed that there should be an 'official scratcher' on every ward, whose other job would be to find hands that had got lost! (1.19.22-32). These examples, together with other conversational exchanges, draw attention to the richness that a focus group methodology brought to this inquiry.

5.8.6.2 Perceptions of care

This section expands on discovery in the context of patients' perceptions of care from others and broadly divides these into 'haphazard' (negative) and 'responsive' (positive) experiences. The quality of care received, and the extent to which communication about it occurred, varied a great deal between individuals and across care settings.

The picture that emerged more often reflected haphazard than well-organised care, though it is possible that specific adverse incidents may have had a greater impact on patients' memories than good everyday care. Episodes of careless lifting and handling causing pain were experienced and described by virtually everyone. Patients described the process of being moved in derogatory terms, such as being 'manhandled', 'yanked' and 'shoved', which indicated not only a perception of themselves as inanimate objects, but of being treated as such by those caring for them. In terms of handling, physiotherapists were perceived as having a level of expertise above that of nursing and care staff and this view was supported by the fact that nurses were implicated more often than therapists in accounts of careless handling:

> ***Chris*** ... the physiotherapists, because they're aware of the human skeleton and the muscle structure they tend to get hold of my arm perfect and hold it in the correct position. Whereas if the nurse is trying to help you get dressed they'll tend to get hold of your hand and pull it up, and um, put you in all sorts of pain. And as I say because it's not their fault it's nothing deliberate or anything it's just um, they're not aware you know basically that's it. 1.11.32-35; 12.1-3

In most cases, nurses' behaviour was attributed to a lack of awareness or ignorance about the vulnerability of a paralysed shoulder, but was further influenced by both dispositional and situational factors. Agency nurses in particular were cited by several patients as lacking the specialised knowledge and training necessary to care for people who had had a stroke. Patients had anticipated that those in authority would have the understanding and experience to deal with them sensitively. When this did not happen and pain was caused, there was a loss of trust and strong feelings of fear and resentment were evoked.

An example of harsh treatment meted out by an agency nurse was described by Jill, who saw it as an unjust punishment for an episode of incontinence that was not her fault.

She was deeply upset by the experience and subsequently made a formal complaint about it. The nurse's behaviour seemed to reflect an insensitive and uncaring disposition as much as a lack of awareness of what could cause pain.

> ***Jill*** And unfortunately a couple of nights later there were some agency nurses on. I'd been ringing and ringing and ringing because I'd spent twenty-two days in ITU. I had to have bedpans because I was having 24/7 I think they call it nursing and um, they had, they didn't come in time so unfortunately I wet the bed which humiliated me dreadfully anyway and the agency nurse was so angry she got hold of my shoulder and yanked me across the bed. Which has made my problem even worse. 4.2.8-15

Nita was incredulous and incensed at suffering the double indignity of being hurt by an ignorant nurse who assumed that she could not feel pain, and then did not believe her when she said that she could.

> ***Nita*** One of the staff nurse she said to me the other er, Tuesday, she said to me, I went to the toilet and she pulled my arm like this and I said, 'Please don't there's such a pain round there.' She said, she said er, 'Strokes don't have any pain.' I could not believe that. 2.7.9-12 ..... I mean I know I've got the pain, why would I make it up? Because the pain is restricting me from so many things. She said, she said, 'Stroke patient don't have any pain.' 2.7.14-16

Events such as this had a profound effect on patients, several of whom would not allow staff to touch their affected arm for fear of harm. In these instances, reflex avoidance behaviours, such as guarding the limb, occurred in anticipation of a genuine external threat, as distinct from guarding as a maladaptive pain behaviour, which can occur, and be positively reinforced by, care and attention from others. The comment from Nita below illustrates this finding and also draws attention to her belief that it would be futile to say anything about her fear of being harmed. She felt disempowered by this situation, which only served to reinforce her anger and resentment at the passive role she was forced to adopt. Although this source of conflict arose from the way she was moved from bed to chair and vice versa using a hoist, not all patients were as distressed by this experience:

> ***Nita*** I mean they come and the way they handle you and I mean you can't say much, they put their hand here and pick you up and, I, I hate the hoist. They need to hoist me and they

> dangle me, some of the nurses couldn't and in the, in the night it totally squashes you, the hoist and I actually so scared of the hoist. But now I don't let them touch my arm, they can't touch it because it's so painful. I could scream. 2.2.23-28

The ease with which pain could be provoked during handling was frequently noted, though the difficulty of being moved by another person was also acknowledged. In some cases, the tolerance shown by patients towards nurses who caused discomfort reflected their acceptance of a situation in which they were passive recipients of care and in which they realised that a degree of pain was sometimes unavoidable. Patients who had less pain were more inclined to be tolerant:

> ***Charlie*** Some of, some of the nurses are very strong. They don't, they don't realise how strong they are and I realise that they have to be strong to lift people around, but they do hurt sometimes. 4.19.15-17

Others were reluctant to complain and explicitly empathised with staff who have a difficult and under-resourced job to do. They cited the conflicting demands of needing to work slowly and carefully with patients who were liable to experience pain, against the need to help a lot of dependent patients to wash and dress in a short space of time.

As distinct from these stressful experiences, patients told of positive encounters. Care was clearly perceived as better in some locations than in others. Where patients had been moved from a 'poor' to a 'good' setting or vice versa, they were able to contrast these experiences with the benefit of hindsight. Trevor gave a vivid example of the effect that good handling had on his morale. He later indicated that had he known what good care was like beforehand, he would not have put up with poor care so readily:

> ***Trevor*** Well, I came into the [Ward] from another hospital and er, you know the [Ward] was, I mean to me it was um, you know, I'd, I'd just sort of er, woken up in the Bahamas or something. I was, it was like a holiday, you know, I had. In terms of drawing a line of where, where, the way I had been treated to how I was treated up at the [Hospital] was so dramatically different. And what I've learnt by being in the [Ward] has allowed me to criticise and understand a lot more that had happened to me prior to that and um, you know, being in the [Ward], the quality of staff um, the way they care for you boosted your morale an awful lot because er, where I'd been before um, that didn't seem to be part of the criteria. 2.16.31-40

Not surprisingly, the kindness that staff showed was much appreciated by patients. They remarked on, and were comforted by, simple attentions as much as by specialised interventions. Nurses who noticed that their arm had fallen down by the side of the wheelchair and re-positioned it, or who took the time to make them comfortable in bed at night were well regarded. The use of heat packs and massage with oils were singled out as especially beneficial. Patients' relatives sometimes initiated these ministrations, bringing in aromatherapy products and oils to be used for massage; those from ethnic minority groups mainly mentioned this.

Prescription of analgesics and 'muscle relaxing' medication by doctors also provided a welcome relief. Patients became knowledgeable about what worked for them and compared notes with others in the focus groups, even recommending different drugs and specific arm supports to each other. Several patients used evocative language, for example, 'terrific', 'blissful', 'absolutely divine' and 'like a miracle' to describe their feelings when pain had been relieved following intervention, which served to emphasise the extent of their prior suffering.

However, the quality of care that patients received was too often seen as a matter of chance, as these next two extracts show. Chris's nurses appear to have been aware of the need to prevent pain from occurring through assiduous positioning:

> ***Chris*** I think I was lucky at the last hospital, the nurses were a bit switched on. They always kept my arm on a pillow and they were very strict about that for my own benefit which I think helped in the long run. 1.1.33-35

Whereas Paul, whose experiences of care had not been as good, and who had spent some time in a 'nice but very under resourced hospital', where he spent all day 'just sitting around', said that on a good day, he'd be lucky if he got half an hour's physiotherapy (4.11.31-35). And on one particular occasion, he had been lucky to get a nurse who knew how to position his arm. This exchange, which followed a discussion about nurses' awareness of positioning and lifting techniques, illustrates the way that group interaction contributed towards the forming of a shared belief about the unpredictable quality of care.

> ***Paul*** ... one night when I was so frustrated I couldn't get to sleep for ages and she actually put the pillow in a position which helped me I must admit. ...
>
> ***Ralph*** That was just luck that you happened to get the right nurse ...
>
> ***Paul*** Yeah
>
> ***Ralph*** ... who knew what she was doing ...
>
> ***Paul*** I think it was yeah. I think, think it was. 4.20.23-30

The belief that their pain was closely linked to their physical losses, and that therapy would have a positive effect on both physical recovery and resolving the cause of pain, appeared to arise from prior experiences, though the strength of that belief was sometimes tenuous:

> ***Jill*** But with the physio I've been having it is starting to ease. But I don't think it's going to go overnight. 4.2.20-21 .... I wish to God that it would, with this hand, but er all you can do is pray. 4.2.23

'Passive' interventions, such as having strapping applied to a subluxed shoulder and being supplied with an appropriate splint or arm support cushion were generally seen as helpful. Participating in more active exercise was perceived as essential and ultimately beneficial, if difficult and painful at times. However, for some patients, the fact that therapy time had to be spent on reversing 'avoidable' problems before progress could be made, contributed towards the belief that having shoulder pain had restricted the speed of their recovery:

> ***Claire*** I think my arm did impede progress because it had got sort of clamped to my side and that was the position which was least painful and it ended up sort of getting stuck there um, which yes, then the physiotherapist had to slowly undo the, the tightness which had happened while my arm had been in that position which led to tightness all down my rib cage which I hadn't realised. And so yes, like Chris, I mean yes, physiotherapy did help but, it was the pain I would, would welcome because I know we were sort of undoing the problem. 1.14.15-22

From an emotional perspective, fear and anxiety were also perceived to hinder progress. As described earlier, some patients who had been roughly handled became hypersensitive to being touched for fear that other people would cause them pain. This limited the amount of 'hands on' intervention they were prepared to accept. Chris, whose care had been consistently good since his stroke onset, nevertheless described fear of pain as causing him to do less well than he might have done in therapy (1.18.12-17). Claire's feelings about hydrotherapy swung from one extreme to the other. Although she enjoyed it and believed it to be beneficial, she found it far less helpful when she felt anxious about her safety:

> ***Claire*** I had hydrotherapy in the pool where I had two physios and it was an enormous luxury. I had two physios working with me so I was just, I was passive and I didn't actually have to work in the water and, that would loosen my arm up and my shoulder would be pain free which was blissful. But I found that where the um, ratio was not quite as high of staff to patients as that um, it tightens up because I'm more worried about how safe I am in the water so I don't actually find it helps. 1.16.2-8

In contrast to the disclosure that fear of pain led patients to reject or avoid intervention, in some situations they concealed pain. Most were able to discriminate between 'harmful' and 'beneficial' pain and were prepared to bear pain that was perceived to be a necessary component of their recovery, as Claire's comments above (1.14.15-22) reveal. Louise endorsed this finding. Though she admitted that fear of pain had caused her to refuse physical contact from nurses, her cognitive appraisal of positive experiences while having physiotherapy led her to conceal her pain, because she believed that if she put up with it her pain would ultimately be relieved and there was a chance that the arm might get better (1.15.27-32). Edward was similar in this respect:

> ***Edward*** Some of the things she does to me is very painful. But it eases off and afterwards its, um, I feel quite good. Specially when you start lifting it high up over the head ... 2.8.1-3 ... Well it's unpleasant to make it move. Because I can't get the arm working and I'm determined to try. Just have to bear the pain during the therapy period. 2.10.12-14

Others also concealed pain, but their reasons for doing so were less clear. Trevor admitted to being stoical by nature; he refused analgesics and kept quiet about pain, preferring to 'grin and bear it'. Louise described an occasion when she suffered in silence, but seemed resentful that no one recognised that she might be in pain. She and others referred to 'not complaining' about pain, which suggested a reluctance to be regarded as someone who made a fuss, preferring to be perceived as forbearing and brave.

> ***Louise*** They not aware the amount of pain one is suffering. They think because you bright and early, you sitting in the bath you bathing yourself, and you capable of doing that little bit, they think everything is O.K. You not complaining so they not aware of the amount of pain one is going through. 1.12.35-39

An interesting insight into concealment of emotional distress, as distinct from the physical sensation of pain, was revealed during a discussion initiated by Victoria about whether nurses should adjust patients' position during the night to prevent morning stiffness and pain. Martin agreed that they should, but then told how nurses could be misled into thinking that patients were sleeping peacefully when they were not.

> ***Martin*** ... they come several times during the night. I felt it a few times myself, you know, when you, when you're sort of in between deep sleep and, and light sleep. If you are waking up, or if you wake up you don't want to show it. So I noticed that someone was looking at me and disappearing again. And in the morning they told me that they saw me sleeping peacefully. ..... They didn't know about the turmoil, turmoil I was in.
>
> ***Diana*** *Right. Why were you in turmoil?*
>
> ***Victoria*** Because of the pain.
>
> ***Martin*** I don't know myself. It must have been. 3.20.18-28

Victoria jumped to the conclusion that Martin had been in pain, perhaps because she could relate to his experience. Martin clearly remembered the incident but was less sure of what had caused it, which could have reflected his memory problem. This kind of difficulty made it hard to determine how much communication about pain had occurred, as patients volunteered more information about painful events and the feelings these evoked than the conversations they had about it. Sometimes it seemed that staff had assumed that patients had no pain unless they indicated otherwise. Otherwise, they were asked by doctors or nurses on their rounds if they wanted anything for pain in general, or the subject would be raised by staff who, it is supposed, would notice signs of pain behaviour during treatment or personal care activities and ask about it. It was claimed that in some settings, no one had brought the subject up at all.

In most settings, formal assessment of pain was perceived to be non-existent, though Edward referred to his physiotherapist asking him to say on a scale of 0-10 how bad his pain was while she was treating his arm. A few patients on a ward where regular assessment had been introduced valued the fact that they had been asked explicitly about shoulder pain. When asked for their thoughts on pain intensity scales, patients gave a very mixed response. Several seemed to find the concept of rating pain intensity difficult because if it was mainly associated with movement or having the arm pulled it would be episodic, being severe to begin with but then easing off. As Trevor said:

> **Trevor** ... the more specific we get the more elusive it seems. 2.26.11

Some believed they could only really express their pain in words, with two favouring the idea of keeping a diary. On the other hand, Ralph inquired, 'What the devil is moderate pain?' (4.26.11) and Victoria asked, 'How can the letters show you how you feel?' (3.18.27-28). Others preferred numbers and some liked the pictorial scale but the visual analogue scale was not generally liked. The faces pain scale (see page 47) received an enthusiastic response from three patients but on further exploration, it was revealed that two thought it conveyed affect. Victoria perceived the faces to reflect her anger, as did Adrian. Paul couldn't understand the expressions as reflecting pain because one looked as though it was smiling. The wish to find a way of expressing their feelings seemed important to several patients, who agreed that they should be asked how they felt about pain as well as trying to score its severity.

Powerful feelings were plainly evoked by experiences of care. Whereas the emotions associated with dependence and awareness of sensory change were mostly unpleasant (frustration, suffering and anger), these largely arose out of the disagreeable nature of their condition, over which patients had no control. In contrast, the emotions associated with receiving care were evoked by other people's behaviour, which was influenced by their knowledge and their ability to empathise and communicate. Though these behaviours were open to change, patients had minimal influence over them. Care was sometimes insensitive and injurious, generating negative feelings of fear, resentment and distrust, and sometimes kindly and restorative, generating positive feelings of gratitude, relief and belief in the efficacy of their care.

To summarise so far, the process of discovery was found to direct patients towards an intimate understanding of their predicament from both personal and situational perspectives. The following section explores how they interpreted their problems further and acted to take responsibility for their condition.

5.8.7 Stage 2: Taking responsibility

5.8.7.1 Developing self-reliance

The transition from discovery to learning to take responsibility for their painful shoulder was mediated by a range of factors and was differentially achieved by each individual. Sensory awareness, the instinct for self-preservation, appraisal of past events and knowledge acquired from health professionals led patients to recognise their needs, attend to their bodies and adopt a range of strategies to manage pain when it occurred, or prevent its onset at other times.

As they were described, these behaviours appeared to be either involuntary or intentional. Nociception could generate a reflex withdrawal from being touched, or prompt attention to the whereabouts of the arm. However, in the absence of nociception, the need to constantly protect the arm from the possibility of harm had to be anticipated and pain prevention behaviours had to be learnt. Some patients instinctively assumed responsibility for holding the arm in bed at night so that they could relax into sleep. Nita had learnt to do this from bitter experience; she appeared to blame herself for the situation she found herself in when she awoke in pain, having not kept her arm close to her body.

> ***Nita*** I get pain too in the night, but I sleep with my hand right over here, holding it all night long. Sleep like this. I can't any other way. The other day I had my arm stretched out and when I woke up and tried to bend the arm. I couldn't even bend my arm. You know it was so tight I thought, 'Oh my God what have I done', so slowly I put it here. 2.6.6-10

During the day, patients preferred to hold the arm near to their body where they could see and feel it, either to ensure that it did not fall off their lap or, when walking, to prevent the shoulder from jarring and causing pain. Patients had to learn to take on responsibility for something they regarded as a separate entity, and which they had difficulty identifying with as a part of their living body. This 'thing' had to be taken around and dutifully watched over:

> ***Claire*** Yes, I've had to learn to be responsible for it, there's part of me which doesn't give me any feedback about where it is. 1.8.9-10 .... you do literally neglect it, you just forget it's there and I've had to learn almost to take um, new responsibility for part of me that isn't registering what's happening to it. It's almost like taking it around.
>
> ***Chris*** That's right, you're always looking for it aren't you.
>
> ***Claire*** Looking around, yes yes.
>
> ***Chris*** To check where it is.
>
> ***Claire*** I feel around in the bed for my arm um to check, because I know it'll lead to pain if I don't look after it. 1.8.15-22

Developing this protective instinct to guard and look after the arm sometimes conflicted with advice from therapists. They tended to recommend positions that kept the arm away from the body to stretch tight muscles and maintain their length as a means of preventing contractures. Though it was understood to be in their best interests, the need to comply with this advice was sometimes outweighed by a patient's desire to adopt positions for comfort and protection.

> ***Trevor*** I think, er you know just looking round the table here now, we all end up developing our own techniques. I'm sure the physios would be not at all pleased to see me sitting here holding my hand, but you tend to adopt that manner because it gives you the maximum amount of protection... 2.7.1-4

As described earlier, once pain was perceived, it could act as a warning system, prompting patients to find ways of alleviating it. Some individuals became expert in recognising the precise position of their arm that was necessary to control pain, and felt that getting this just right was sometimes the only intervention they needed to obtain relief:

> ***Peter*** ... immediately you put your arm sort of in the straight position again it goes, and it's not a pain that continues. You don't sort of really want medicine to control it, all you want is to grab hold of your hand and push it across or back.

> ***Chris*** I've experienced exactly the same. I find that if, providing I keep my hand here, the pain can go away almost instantly. 1.4.26-31

Health professionals were generally thought to offer helpful solutions to prevent and alleviate pain, and these interventions sometimes sufficed. However, patients realised that they did not have all the answers. In these circumstances, they developed their own ways of coping and compensating for loss of control over their bodies to make everyday tasks easier for them. Getting their pillows in exactly the right position at night was seen as critical for comfort. After discussing different ways of arranging pillows among themselves, one group was asked if they had found this out on their own, or if positions had been suggested to them. This exchange illustrates how the conviction that pain could prompt self-help developed, and was reinforced, within this group:

> ***Claire*** No, I didn't get any suggestions, no one suggested anything to me.
>
> ***Chris*** I think pain makes you look for a way.
>
> ***Rosemary*** *Right.*
>
> ***Chris*** If you're hurting you'll do something to try and stop it won't you.
>
> ***Louise*** Yes, you find your own comfort, your own relief. 1.11.23-27

Members of other groups endorsed this finding. Jill tucked her arm down the waistband of her trousers when she was walking to stop it from hurting and to prevent her from overbalancing, and Trevor played around with his wheelchair arm rest and developed an elaborate system involving pillows and strapping to hold his arm in position. Several patients had learnt for themselves how much easier it was to get dressed in big baggy T-shirts or clothes made from stretchy material. As Claire pointed out, the determination to gain pain-free control over the body stimulated the search for solutions such as this:

> ***Claire*** I think it's, it's the sort of, the fact that it also gives you independence. As you said, it's easier for you to get dressed in and um, that was pretty important to me that I should be able to do things myself and not to have to be helped. 1.13.15-18

The struggle to achieve independence reflected the strength of will of some group members. Several described floundering about, trying to find their lost arm and get comfortable by themselves, rather than calling for help. Paul, who was five months post-stroke, told of the effort it took him to remember and implement instructions aimed at correcting the muscular imbalance around his shoulder so that he could gain control over his posture and reduce pain while walking (4.3.3-7). Although he understood the rationale for this, actually mastering control over his unpredictable body so that he could rely on it again was not easily achieved. On the other hand, a few patients, who tended to be those whose stroke was of more recent onset, appeared to be passive recipients of care, only showing self-reliance to a limited degree:

> ***Charlie*** I don't think I'm in any position to give any advice being in pain on my, by myself. ..... Obviously you use the pain, the painful arm as little, as little as possible unless it's under supervision. 4.19.2-6

The next section develops the theme of taking responsibility further by considering it in the context of relationships that formed between patients and the staff caring for them. The term 'informing' is used in the sense of enlightening staff about the problems of post stroke shoulder pain in general, as distinct from simply telling them about specific incidents, though these were sometimes the starting point for conversations about pain.

5.8.7.2 Informing professionals

Having achieved a degree of knowledge about their changed body, the nature of their pain and the quality of their care, patients were in a better position to try and address situations of conflict and to share their personal expertise with those looking after them. Though developing a rapport with professionals was seen as desirable, this was harder to achieve with doctors and nurses than with therapists, who generally spent more one-to-one time with patients and were more likely to be present on a consistent daily basis during their stay in hospital. Furthermore, as seen from Chris's comments on page 103, which were echoed by patients in other groups, therapists were regarded as having more specific knowledge of anatomy and movement and a better understanding of issues surrounding lifting and handling than doctors or nurses.

Patients tried to deal with situations where poor care had caused them unacceptable harm by reporting it, but were not necessarily satisfied by the response they obtained. Having been hurt by being lifted badly, Ralph decided to solicit help by saying something about it to a doctor. The unsympathetic response he received, and the lack of any sort of suggestion as to whether this kind of problem could be solved, or at least minimised, dashed his expectations of support, causing him to accept the situation grudgingly, but to project his annoyance onto his dependency:

> ***Ralph*** I complained to the doctor the next day about that. ..... Because it left me with a really aching shoulder. As if you'd been hit with something, like bruising the pain was.
>
> ***Rosemary*** *And, what did the doctor say about it?*
>
> ***Ralph*** He just said, 'Well they're going to have to move you, you know, there's not much I can do about the nurses moving you.' I agree, they do have to move me I suppose. Why did they have to move me, why can't I move myself? 4.16.21-29

Previous negative experiences of care had a potent effect on the way patients behaved for their own protection. Some, anticipating problems, made direct comments to nursing staff to alert them to the possibility of causing harm. Trevor said that, having discovered the vulnerability of his arm and the heavy handed way in which he had been 'manhandled' in the past, he wouldn't let the staff 'get away with it now' and would either criticise any of them who caused pain 'very vocally, and get them to stop' (2.2.7-9) or 'almost be forced to react physically' (2.17.14-15). The more assertive among the patients, who were aware that there were no outward signs of anything being wrong when their shoulder was hidden under clothing, felt constrained to use powerful language in order to get their message across:

> ***Claire*** I think if anyone has approached me to help me I've said, 'Don't, don't help me with my left arm', and I think I've said that because of the shock value, I've said, 'You'll, because you'll dislocate it.' Because it's more effective than saying, 'Don't help me.' 1.5.35-38

Where problems arose with the performance of personal care activities, some patients took on the task of trying to explain the dilemma to staff and to give them directions on the best way to handle the arm. While they hoped that raising the issue would minimise pain, they came to realise how complicated the whole procedure could be. A practical drawback arose from the difficulty of translating precisely what they wanted done into words and gestures that could be understood and acted on by another person with less insight into their problems.

> ***Nita*** Yes, I say, 'Please don't, don't pull, no good because it stuck here, you have to put this sleeve first, push it round.' But the other thing is you can't lift your arm, so you can't push it too much. Very painful. 2.15.14-16

Louise told how she had to work slowly one step at a time with some nurses because they didn't have any idea of how to help her get dressed. Though this partly solved the problem of her experiencing pain during dressing, it created a dilemma of a different kind. Despite being able and willing to take responsibility in this way, she believed that the nurses resented this reversal of roles and was afraid they would be angry and regard her as patronising. She would have preferred someone else to take on the role of instructor and was grateful when her physiotherapist organised a practical teaching session for this purpose; indeed, it was almost unanimously agreed that nursing staff should have more training from physiotherapists with specialist knowledge of positioning, lifting and handling:

> ***Louise*** .... sometime you feel you intimidate them. To tell them, 'No don't do this, don't do that' is patronising, because you are telling them that they don't know their job. So they don't want to learn from you. They have to be shown with someone who knows about this for them to be good professionally in handling patients. 1.14.32-38

While several patients were prepared, and on occasions constrained, to take on the role of 'teacher', they were not confident about it. A paradox had become apparent in that on the one hand, patients still perceived themselves as dependent and expected therapeutic care from others with greater knowledge and expertise. But on the other hand, their own insights into their changed bodies, their pain and the nature of the care on offer brought the realisation that their own knowledge and understanding was in many ways superior to that of some 'experts'. As Jill succinctly put it:

> ***Jill*** We'd all make very good rehab nurses we would. 4.16.16

To end on a more positive note, in some settings good collaboration was perceived to have been achieved between patients and members of their rehabilitation team.

Furthermore, in these settings, team members were seen to be working closely together and communicating well. Louise, who was as expert a patient as one could have wished for, having experienced care in five different hospitals across two countries during the six months since her stroke, recognised the value of a good team. In this final extract, she conveys what she saw as the ideal way of working.

> ***Louise*** Good communication between nurses and the patients and the team has to share the responsibility amongst themself. I think physios should not do just the job of getting us on our feet they should teach the nurses exactly how to handle the patient. Because otherwise from physio you go to the ward, the nurses completely different, it's not very good. And I find the communication of that in the [Hospital] was very good. There was a good team and they work together. 1.27.27-33

Louise summed up what members of other groups had said when she made these comments. Indeed, there was agreement on a number of issues, which are discussed in the next section.

5.9 Discussion

These findings have been synthesised into a detailed account of the experience of post-stroke shoulder pain and communication about it in the social context of hospital settings. Some aspects of patients' experiences have been omitted because they were not relevant to this thesis; patients sometimes strayed from the subject of shoulder pain to raise further issues of importance to them, such as the history of their stroke onset. However, other peripheral matters helped to convey the complexity of the problem so are included. The appropriateness of the focus group method and of IPA to this inquiry will be addressed first. Following this, some issues of particular relevance to pain assessment will be discussed.

5.9.1 The focus group method and its analysis

Though patients were homogenous to the extent that they all had shoulder pain after a stroke, they had different combinations of physical and psychological impairments. Each individual had varying experiences of pain. These differences, taken with individuals' distinctive characters, gave each group a unique quality of its own. The combination of personalities influenced the distribution of talk but the effect that this had on patients' capacity for self-reflection was unclear. Although a dominant member could have inhibited someone who was less forthcoming, in group two it seemed a distinct advantage to have one chatty member along with the two quieter ones to create a friendly atmosphere and keep up the conversational momentum.

As evidenced by the findings, patients' reflections were detailed and wide-ranging. The social interactions that were stimulated within the groups enabled them to compare and confirm thoughts and feelings about the events that had befallen them, to form and articulate shared beliefs and moreover, stimulated memories of past episodes, taking the conversation in unexpected, but worthwhile directions. In some instances, patients sought reassurance from one another about unexplained symptoms. Not only did this indicate their concerns and uncertainties, but it also showed how they benefited from discussing their problems with other people who had shared similar experiences.

The network of experiences conveyed by members of the first group was recreated with similarities and differences across subsequent groups and provided a rich source of material for analysis that, it is claimed, had equal authenticity to material that might have been obtained from individual interviews. Every patient was empowered to have their say to some extent, though some were more confident than others. Three made significantly fewer contributions than other members of their groups, which draws attention to a limitation of this method. It could be that deeper insights would have emerged had they participated in one-to-one interviews instead. But on balance, the choice of method was well suited to the purpose of this inquiry.

IPA seeks to uncover what people think and believe about a common experience. Shared themes are organised to convey the essence of the experience in their own words and to produce an account of its meaning. In keeping with the principles of IPA as a double hermeneutic, the findings here are woven around what patients said during the discussions; they spoke for themselves in making sense of their world. However, the way the extracts have been grouped and the interpretations offered represent my construction of their meaning. Another person might uncover different insights.

From an epistemological perspective, Sim (1998) points out that participants' expressed thoughts and beliefs may be altered by the influence of focus group dynamics, since group data is tied to a particular context of interaction. He questions the capacity for any analytical process to disentangle social factors operating at group level from individual factors. This argument centres on the authenticity of meanings formed under different circumstances, which is indeed a matter for conjecture. There were instances in this study where shared meanings were formed as part of the group process and it cannot be discounted that alternative meanings might have emerged and been analysed differently if data had been collected from individual interviews. On the other hand, beliefs may have been formed precisely because conversational exchanges prompted their articulation. For instance, this appeared to be so when two patients discussed the unpredictability of their care. The possibility of an individual being influenced by others when affirming a belief must therefore be offset by the possible emergence of beliefs that might otherwise have remained latent.

Identifying similar and contradictory themes during the analysis was assisted by the tendency for group members to reinforce each other's experiences and beliefs where they were alike, and to disagree with them if they were different. Where a shared view was reiterated across groups, for example, the belief that some nurses were careless about lifting and this was because they lacked knowledge, its veracity was strengthened and tentative generalisations could be ventured. Where contrasting accounts were given, for instance when describing the acquisition of self-reliance, a continuum of experience could be identified.

5.9.2 Reflections on validity

I believe that I approached this study aware of the importance of impartiality. Nurses had genuinely seemed to come in for the most criticism by participants whereas physiotherapists were seen as having greater knowledge of lifting and handling. But it was possible that I was positively biased towards my own profession. Rosemary, as a nurse, might have taken a different view and I recognised the importance of giving her the opportunity to challenge my findings. As a check on my fairness, she read through the finished text. Whilst she agreed in principal with my findings, she pointed out that the type and frequency of contact between patients and members of different professional groups varied and that the opportunity for problems causing pain to arise was greater for nurses than for other professionals. Furthermore, that therapists can stop what they are doing at any time if needs be whereas a nurse, for example, has to complete a hoisted transfer once it has begun. Whilst these were all fair comments, they did not alter the underlying analytical framework, but rather explained it from an alternative position and highlighted the crucial importance of investigating the matter further from this very perspective so as to present a balanced view of the problem.

5.9.3 Issues of relevance to pain assessment

In the clinical setting, assessment of pain entails obtaining information about it from a patient to assist diagnosis, inform management and to use as a measure of outcome. From the perspective of the patients who participated in these focus groups, assessment of their shoulder pain was inadequate in both a formal sense; that is structured pain rating instruments were rarely used, and in an informal sense, since 'everyday' communication about pain was seen to be random. Some difficulties over assessing pain appeared to arise from patients' perception of it in the context of their impairments. Other problems seemed to arise from lack of awareness on the part of hospital staff. Several patients expressed resentment about this and would have liked staff to make the first move in asking about pain. It is not known whether they felt the same about their other physical and sensory losses. Moreover, the extent to which stroke patients in general communicate about their arm impairments with health professionals is unknown, so the interpretation of findings here could be biased by not having explored this further. It would be informative to compare interactive experiences in a cohort of patients without shoulder pain recruited from the same settings as those with pain whose experiences were recounted here. This could reveal similarities and differences in communication needs between patients with shoulder pain and those without.

5.9.4 Beliefs about pain and injury in the context of sensory changes

Patients suffered degrees of sensory loss that was regained over time to a greater or lesser extent. Once the capacity for nociception had recovered (for some it had not been lost), they could begin the complex task of working out associations between pain and the physical and psychological stresses that they assumed had evoked it. From their cognitive appraisal of past experiences, some believed that they had been repeatedly injured without knowing it at the time, and that this could have caused their shoulder pain. There were numerous opportunities for trauma of this kind. Patients were almost unanimous in attributing pain to one or more of the following: The arm falling off their arm rest, being pulled by other people during personal care activities, being awkwardly positioned for long periods of time or worst of all, rolling on to the arm at night. Being hoisted from bed to chair or vice versa was cited by a few, along with walking when the arm was left to dangle. This association between shoulder pain and poor positioning/handling has long been suspected. Although only tenuous evidence for this has come from research (Ratnasabapathy et al., 2003; Ring et al., 1993; Wanklyn et al., 1996), the findings in this study reinforce anecdotal evidence from other stroke patients (Bauby, 1997; Cant, 1997; McCrum, 1998).

The lack of concordance between pain and injury is well described in the pain literature and has been shown in stroke (Ploner et al., 1999). In rare cases where people have congenital analgesia, though they are cognisant of the dangers, trivial injuries to the joints nevertheless go unnoticed. Without appropriate rest to the damaged area, a chronic joint problem can become established (Melzack & Wall, 1988). The potential for serious injuries in patients with neurological conditions if the neural transmission of pain is absent or diminished has also been described (Bleeker & Mulderij, 1992). In the case of stroke, difficulties arising from attentional deficits, neglect and poor memory make it a particularly challenging problem.

With the benefit of hindsight, some patients believed that the cumulative effect of successive episodes of minor trauma to an initially insensate arm, both unwittingly self-inflicted and resulting from careless handling, played a part in the genesis of their shoulder pain. Thus their initial awareness of pain onset may have reflected the time at which nociception recovered, rather than the time when tissue damage first occurred. This has clinical implications because a patient's first report of pain onset is often taken to coincide with the timing of their recent injury and is the trigger for staff to initiate appropriate intervention to treat the cause and to limit further damage. This assumption is questionable.

5.9.5 Learning to manage pain in the context of sensory changes

Patients were troubled by their arm's apparent dissociation from the rest of their body and by the muddled and unpleasant sensations that they experienced. They explored these feelings, scrutinising and touching the arm to see if they could regain some sense of ownership over it. This finding is not exclusive to those with shoulder pain, since others have also described patients who see their paralysed arm as an object to be talked to and controlled, regarding this to be an increasingly frustrating exercise as time moves on and recovery slows down (Doolittle, 1992; Ellis-Hill, 2000). Nor is it peculiar to stroke. Sacks (1991), who suffered peripheral nerve damage following an injury to his leg, tells a similar story. He writes as a neurologist and as a patient when describing the impact that feelings of alienation and dissociation had on his conscious awareness. Although he realised that his leg was objectively still there, he could no longer relate to it as a real part of himself.

> I could say that I had lost the leg as an 'internal object', as a symbolic and affective 'imago'. It seemed, indeed, that I needed both sets of terms, for the inner loss involved was both 'photographic' and 'existential'. Thus, on the one hand, there was a severe perceptual deficit, so that I had lost all feeling of the leg. On the other, there was a 'sympathetic' deficit, so that I had lost much of my feeling *for* the leg. Both were implied in the terms I used – the sense of my personal, living, beloved reality having been replaced by a lifeless, organic, alien dissolution of reality (Sacks, 1991; page 50).

Despite his professional knowledge and intact cognitive capacity, he felt constrained to explore the status of his leg repeatedly, both by himself and by enlisting the help of hospital staff. He had no immediate insight into why these curious feelings existed, but rather pieced together experiences over time until he was eventually able to understand his deficit and re-frame his body image. In this group of stroke patients, experimentation over time raised awareness of their wayward, painful arm prompting them to learn about it and care for it. Doolittle (1992) also saw experimenting with physical activities as a learning process, enabling stroke patients to recognise their capacity to make progress.

The theory that neglect could be associated with the genesis of shoulder pain was supported by patients' accounts of how maintaining conscious awareness of the arm to ensure that it remained safe required constant concentration. The intense mental discipline required to preserve the body's position and prevent harm in the face of profound sensory loss has been described by others, though in different circumstances (Cole, 1995). The difficulty these stroke patients experienced in attending to their paralysed arm was evident. They found this an onerous duty and when they forgot the arm or lost it, which occurred frequently, they sometimes blamed themselves for the pain that ensued. When this happened, nociception prompted attention, reminding patients of the need to identify what had happened to the arm and deal with it. Thus a cycle of *nociception – awareness – self-care – forgetting – nociception* initiated the slow process of learning to understand and independently manage their painful arm.

5.9.6 Perceptions of care and its implications

Whether repeated minor trauma is a primary cause of pain or whether it exacerbates damage already caused by biomechanical derangement cannot be answered by this study. What is of more importance, though, is the unequivocal belief held by this small group of patients, that there was a strong association between the two, and that many hospital staff lacked knowledge about this association and its risks. While this finding cannot be generalised to staff in all settings, it was based on the perceptions of patients with differing types of pain who recounted experiences of care in a total of 19 different in-patient settings, ranging from general medical wards to specialist neurological units. This has important implications for pain evaluation in clinical settings.

Staff ignorance and the carelessness that ensued had extensive repercussions, not only causing additional pain and injury, but also considerable fear and resentment. Cant (1997) described his sense of disempowerment on becoming a stroke patient in hospital. He felt like a commodity and had to *'learn the rules of the new game'* he was being *'forced to play'*. Patients in this study felt much the same; perceiving themselves to be inanimate objects, manhandled by nursing staff who were sometimes more like workers trying to meet a deadline than attentive carers. The rules of the game they had to play were complex. Their shoulder problem was only one of a range of physical and psychological difficulties that competed for attention. They were obliged to submit to care that was perceived to vary along a continuum from deficient to excellent, and that was delivered by a diverse group of people. They were never quite sure what to expect from an unfamiliar member of staff; they wanted to be able to trust those in authority but sadly, this trust was sometimes misplaced, which lowered their morale, created a sense of insecurity and for some, led to a fear of being moved.

A state of fear and anxiety can exacerbate nociception, as well as being one of a number of emotional responses that are evoked by the experience of both acute and chronic pain (McCracken et al., 1992). The relationship between fear, anxiety and pain was difficult to interpret from these findings because each individual was different in character, as well as having encountered varying experiences. However, some found that both pain and fear of it affected their participation in physiotherapy and several claimed to have rejected intervention from nursing staff that was perceived to be potentially harmful. Even Trevor, the self-confessed stoic, claimed he had been moved to react in anticipation of pain. This indicated a fear-avoidance mechanism at play. The fear-avoidance model first proposed by Lethem, Slade, Troup, & Bentley, (1983) relates fear and pain to behaviour through avoidance learning. The maintenance of this cycle carries the risk that patients in the acute phase of pain will develop a chronic pain condition because of a fear that movement will increase both pain and injury. This in turn leads to a withdrawal from functional activities, perpetuating more stiffness and pain (Philips, 1987; Vlaeyen & Linton, 2000). The implications for assessment arise from the need to pay attention to both somatic and affective components of pain.

5.9.7 Barriers to communication about pain

It appeared that routine communication about shoulder pain was infrequent and that barriers to it came from both staff and patients. Patients alleged that unless they said something about it, nursing staff presumed they were either not in pain, or were unlikely to develop it when being moved or handled. In other words, staff did not ask questions about pain because the need to ask questions was not recognised. This was believed to reflect a lack of knowledge and inadequate training in the care of stroke patients that was particularly noticeable in the case of agency nurses. Patients believed that physiotherapists' knowledge was superior to that of nurses because they had experienced the way physiotherapists handled them. They either caused less pain, or if they did cause pain, it was perceived to be an unavoidable part of therapeutic exercise that was not detrimental to them. Sometimes pain was discussed during the course of therapy and sometimes it was concealed.

Patients who admitted to concealing pain in various circumstances did so either because they were stoical by nature or because they did not want staff to think they were the types to whinge. It appeared that a variable combination of deficient knowledge on the part of nurses, patients' concealment of pain and the inference that each expected the other to make the first move in communicating about it, contributed to nurses sometimes being oblivious to patients' shoulder pain. Thus research studies which have relied on patients' *'spontaneous report'* of pain (Jespersen et al., 1995) should be viewed with some caution. Lack of awareness by hospital staff of other 'invisible' deficits in brain damaged people has also been found to lead to misinterpretation of their problems (Swift & Wilson, 2001). Educating staff about the risk of making assumptions in the absence of signs of pain and suffering is clearly important. In addition, raising awareness of the emotional impact of pain, in particular the effect of anger and resentment on relationships with staff, would contribute to a greater understanding of patients' problems.

These findings call into question a wider issue; that is the validity of formal proxy reports of pain status made by health professionals, since patients seemed to think that staff often did not know when they were in pain or how severe it was. Whether this was in fact the case is, of course, not known. Moreover, whilst the patients who participated in these focus groups were all sufficiently articulate to express their problems should they have chosen to do so, and indeed many of them did, there is a much greater potential for misconstruing pain in patients with more severe language and cognitive problems.

5.9.8 Taking responsibility for pain and initiating dialogue about it.

Patients' ability to assume responsibility for their painful arm appeared to arise from their acquired self-knowledge, cognitive appraisal of their situation, anticipation of the problems they might meet in various circumstances and the motivation to help themselves. However, acting to solve their problems was confounded by the sheer difficulty of manipulating their heavy, non-compliant arm, together with frequent episodes of simply forgetting that it existed at all.

Although one must be cautious about making inferences from an absence of findings, it is notable that patients did not refer to having any interventions targeted to improving awareness of their arm, and thus to foster their ability to take responsibility for preventing pain. Rather, prompting seemed to occur on an ad hoc basis, with staff either telling patients to, *'pick your arm up'* when they noticed it hanging down by the side of their wheelchair, or re-positioning it for them. It has been shown that sensory loss after stroke can be alleviated by re-training in both early and late stage patients, and that this may be accompanied by recovery of functional sensory-motor linkages impaired by stroke (Yekutiel & Guttman, 1993; Yekutiel & Soroker, 2003). Furthermore, compensation for sensory loss by developing visual awareness of body position through repeated practice may be critical to the acquisition of independence (Cole, 1995). It is possible that greater focus on these strategies could be of benefit.

The groups revealed a spectrum of self-help behaviours. These spanned a continuum where at the one end, patients remained passive recipients of care whilst at the other, they developed their own innovative strategies to prevent pain during functional activities, and struggled to get along without help so they could experience the satisfaction of having mastered these achievements for themselves. This sense of self-empowerment may reflect a growing cultural change within medicine that has seen patients question the nature of their care and the wisdom of others who are supposed to 'know best'. In assuming this responsibility, patients became experts in their own condition, but in the absence of dialogue between them and the staff caring for them, the benefits of their expertise were lost. Kennedy (2003) suggests that:

> Caring for a patient requires both parties to recognise and respect the other's area of expertise. Together they can pool their knowledge and choose the way forward (Kennedy, 2003).

Pooling of knowledge about shoulder pain was not revealed as a common occurrence by the patients in these groups, an omission that needs to be rectified, however minimal the contribution that some patients may be capable of. Though a few patients assumed the role of 'teacher', they felt self-conscious about doing so and were worried about being perceived as patronising. The way they described some exchanges between themselves and staff indicated a tension in the relationships that was a poor basis for promoting mutual understanding.

But are health professionals as poorly informed as this study would suggest? The next chapter will take a look at the problem from a different viewpoint, that of a group of hospital staff caring for stroke patients without the ability to describe their experiences in the way that these focus group participants were able to do. This will add a further dimension of understanding to the interactive process of pain communication.

Chapter 6

Detecting shoulder pain in stroke patients

6.1 Chapter outline

This chapter describes the second qualitative study, which investigated how health professionals obtain information about shoulder pain from stroke patients who have difficulty articulating their problems. This study centred on the observation of shoulder pain behaviours in clinical settings. After explaining the reasons for choosing this as a relevant area to research, the advantages and disadvantages of several alternative methodologies are discussed and the final decision to use a critical incident interview technique is justified.

In the methods section that follows, the initial pilot study that informed both the conduct of the main study and the analytical framework used to generate the results is described. A report of the main study is then presented. This details the procedure followed and some of the difficulties that arose during its course. The results section describes the participants and gives a breakdown of findings. Observed pain behaviours are defined and classified by type and in hierarchies of perceived intensity. The interactive processes that staff used when judging whether these behaviours were a consequence of shoulder pain are described. Finally, the appropriateness of the method is considered and the results discussed in relation to previous research and communication about pain in clinical settings.

6.2 Introduction

It was suggested in the last chapter that health professionals should be more proactive in eliciting information about post-stroke shoulder pain. If patients are able to communicate freely, this information can be sought by staff regularly asking the 'right questions', or by using suitable pain rating scales. However, those with severe deficits of language and cognition can neither communicate about their problems freely nor use rating scales reliably. They are entirely reliant on the ability of other people to determine when they are in pain through observation of their behaviour.

To gain a better understanding of shoulder pain behaviours could have two benefits. Firstly, a systematic study of them would make a valuable contribution towards the development of a formal behavioural assessment of shoulder pain for patients who are unable to use self-report methods of conveying information about it. Secondly, educating staff about behavioural responses to shoulder pain would further raise awareness of it in all stroke patients in ordinary everyday situations.

As so little is known about how staff in hospital settings recognise shoulder pain in stroke patients, this became the next priority on the research agenda. Therefore the aim of this study was to investigate how hospital staff obtain information about post-stroke shoulder pain in terms of the behavioural signs that alert them to its presence.

6.3 Rationale for the study design

Whereas a focus group methodology was well suited to an exploratory study of patients' inner experiences of pain and its communication, it was less appropriate for a study investigating how expressions of pain are received and understood by 'outsiders', on a one-to-one basis. To provide effective, systematic assessment of pain, specific information about individuals that can be interpreted, documented and acted on by members of the health care team must be obtained. For this practical reason, a more structured approach was chosen for this study.

Various methodologies have been used to identify pain behaviours as a first stage in the development of behavioural rating scales for patients with various forms of chronic pain and cognitively impaired individuals (see Chapter 3 pages 51-57). Of these, the following were considered: Collating descriptions retrospectively from medical notes (Vlaeyen et al., 1985), systematically documenting videotaped behaviours displayed by patients in contrived situations, for example, performing standardised physical activities (Dekker et al., 1993; Keefe & Block, 1982; McDaniel et al., 1986; Simons & Malabar, 1995), and using interviews to prompt general recall of observed behaviours by health professionals and primary caregivers (Parke, 1998) (McGrath et al., 1998; Weiner et al., 1999).

6.3.1 Descriptions of pain from medical notes

Collating descriptions from medical notes was considered but rejected for the following reasons. To start with, pain in general has been found to be poorly recognised, assessed and documented in health care settings (Blomqvist & Hallberg, 1999; de Rond, de Wit, van Dam, van Campen et al., 2000), the more so in patients with communication deficits (Sloman et al., 2001). Besides, a review of the literature prior to development of the integrated care pathway on the RRU (see pages 2 and 3) had revealed no precedent for recording shoulder pain behaviours in stroke patients unable to self-report. Even on the RRU, where staff knew that a review in management of post-stroke shoulder pain was underway, and where formal shoulder pain assessment had become routine, records of shoulder pain behaviour in the case notes were limited. It is therefore unlikely that this method would have yielded an adequate data set.

6.3.2 Detection of pain behaviours from videotapes

Seeing whether health professionals could detect and describe signs of pain from videotaped recordings of patients participating in specific activities would have allowed intra-rater and inter-rater reliability to be determined. However, there were disadvantages. Firstly, awareness of being videotaped could introduce bias from the Hawthorne effect; that is people behave differently when they are conscious of being observed and patients might exaggerate or suppress their symptoms. Secondly, the behaviours disclosed in a contrived setting would not necessarily reflect clinical reality because they might vary from those shown in private, such as when bathing, transferring to the toilet or moving in bed at night. Focus group patients cited all these activities as causing pain, but recording them would be unacceptably intrusive and problematic. Lastly, those watching the videos would have advance knowledge of what they were looking for and could be artificially sensitised to pain behaviours.

Nevertheless, this methodology was piloted to explore its potential usefulness. This was facilitated by an earlier study, set up by a group on the RRU, to determine the procedures that senior physiotherapists used when assessing the hemiplegic shoulder. The objective had been to devise a tool for teaching students and junior staff how to structure an assessment and to develop the clinical reasoning skills that go with it (Bond, Ross, & Turner-Stokes, 2001). As part of the development process, a set of videotaped shoulder assessments was analysed. A sub-set, featuring four patients with shoulder pain, was made available for secondary analysis of pain behaviours. Two patients had been assessed once each by different physiotherapists and the third had been assessed on two separate occasions by two other physiotherapists. The Harrow Research Ethics Committee had approved the study and patients had given their informed consent.

These videotapes were watched one by one by the researcher, who noted pain behaviours as they were perceived to occur and recorded what the physiotherapist was doing at the time. Table 6 lists the (unrelated) behaviours and activities noted.

Table 6:
Perceived pain behaviours and physiotherapists' activities

Patients' perceived pain behaviours	Physiotherapists' activities
Facial grimace	Observing the patient
Touching the shoulder or upper arm	Asking a question
Rubbing the shoulder or upper arm	Touching the patient
Protecting the shoulder or upper arm	Palpating the shoulder or upper arm
Flinching	Performing a passive movement
Vocalisation (non-verbal)	Verbally instructing the patient to move
Vocalisation (verbal)	Other
Ambiguous	
Other	

A grid was drawn up with pain behaviours listed down one side and physiotherapists' activities across the top. The four videotapes were then viewed by a psychologist and a physiotherapist researcher, who independently ticked the relevant grid area when noticing a behaviour during an activity. Subsequent review revealed that although there was consensus over a few behaviours, there was a considerable degree of uncertainty over others. The grid sheets had almost as many written comments and question marks on as ticks, making it meaningless to evaluate agreement.

The patient's face was concealed during some parts of the assessment; notably when lying down, so facial expressions of pain could not be seen. Furthermore, some expressions were equivocal. For instance, it was hard to discriminate between grimacing as a pain behaviour as opposed to a response to being touched by a physiotherapist with cold hands or a response to the effort involved in raising a partially paralysed arm. Moreover, voluntary resistance to being moved could be confused with involuntary resistance due to increased muscle tone. Shifting of the body position could as easily have been due to a feeling of instability as to avoid a painful posture. It became evident that ambiguities such as these warranted clarification from the assessing clinician, who would be more likely to give a reliable interpretation of behaviours from hands on contact with the patient than could be gained by observation at second hand. Having considered all these points, video recording was rejected as a method.

6.3.3 Identifying pain behaviours from interviews with caregivers

The final methodology considered was to investigate shoulder pain behaviours in clinical settings using one-to-one interviews with staff as a means of data collection. This method has been used in an ethnographic survey of pain in cognitively impaired older adults (Parke, 1998). Furthermore, semi-structured interviews with family caregivers have informed the development of a pain assessment instrument for non-verbal cognitively impaired individuals (Breau et al., 2000; McGrath et al., 1998).

It was held that this method would have the advantage of being ecologically valid and would largely address the limitations of observing videotaped behaviours described above. On more theoretical grounds, pain communication has been depicted as a complex transactional process, in which one person makes judgements about the occurrence and nature of pain from observation of another's behaviour. It is argued that to tease out this process; that is to find out how staff decide that the behaviours they observe in individual patients in the context of everyday clinical care are due to shoulder pain, careful, questioning about specific episodes of pain is necessary.

Though structured, semi-structured and open interviews all lend themselves well to gathering detailed accounts of complex social interactions, they can be time consuming for clinical staff working in a busy hospital ward. As the need in this study was to identify factual descriptions of particular shoulder pain behaviours as distinct from, say, exploring beliefs about the aetiology of post-stroke shoulder pain, it was decided to conduct semi-structured interviews using the critical incident technique.

This methodology was first developed during the 1940s for use in the United States Army Air Force (USAAF) Aviation Psychology Programme. The purpose was to provide the factual basis for solving practical problems affecting work force proficiency. For example, in one USAAF study, accounts of pilot disorientation informed changes in instrument design and officer training (Flanagan, 1954).

On-going development has led to the critical incident technique being extended to civilian settings, where it has been used for the systematic study of a variety of human behaviours. More recently, it has been used in health care settings to investigate components of best nursing practice (Tolson, Smith, & Knight, 1999), indicators of quality of care (Grant, Reiner, & Bannatyne, 1996) and patients' behavioural responses to their carers (Kemppainen, O'Brien, & Corpuz, 1998). In general, the technique can offer insight into patients' needs, elucidate the complex and varied interactions that occur between patients and health professionals, assist in identifying specific behaviours related to management and thus inform the development of guidelines for improving the quality of patient care (Kemppainen, 2000). It is defined thus:

> 'By an incident is meant any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act. To be critical, an incident must occur in a situation where the purpose or intent of the act seems fairly clear to the observer and where its consequences are sufficiently definite to leave little doubt concerning its effects' (Flanagan, 1954; page 327).

While Flanagan (1954) agrees that documenting observations of people's behaviour is commonplace, he argues that the advantage of this refined technique lies in its set of principles for collecting multiple factual accounts of human behaviour having particular significance and meeting defined criteria. In brief:

> 'The essence of the technique is that only simple types of judgements are required of the observer, reports from only qualified observers are included, and all observations are evaluated by the observer in terms of an agreed upon statement of the purpose of the activity.' (Flanagan, 1954; page 335).

In this case, the simple judgement required is that the patient in question has shoulder pain. Health professionals are the observers qualified to report on pain, and the agreed statement of purpose is to describe the behaviours that suggest to the observer that the individual patient has shoulder pain.

The principal disadvantage of using the method to collect retrospective accounts of incidents is that it relies on accurate recall. Given the rapid turnover of patients in acute hospital settings and the shift patterns that mean staff are not always responsible for the same patients from day to day, some recounted observations could be misconstrued leading to data being given false credence. Though this limitation is equally likely in other forms of interview, the dependence on detailed factual information about behaviour that is the hallmark of this method makes precision all the more important.

To some extent, this problem may be overcome by the distribution of information leaflets beforehand, since participants are more likely to remember observed shoulder pain incidents if it is known in advance that they will be asked about. It is also advantageous if the interview can take place soon after the behaviour has been observed; though as pain events cannot necessarily be predicted, this poses practical difficulties. Another way of countering this limitation would be to collect data prospectively, by asking staff to write an account of incidents in which pain behaviours were noticed immediately after they occur. However, this would both interrupt patient care and make unacceptable demands on clinical staff, many of whom find completing additional paperwork problematic during their busy working day.

Nonetheless, the large sample sizes generally used in critical incident interview studies increases the likelihood of a number of independent observers making similar observations, which adds to their credibility. Coping with such numbers is made possible by the brevity and clearly focused questioning that characterises the method. And finally, the disadvantage of recall bias must also be balanced against the advantage of obtaining first hand factual information about specific pain behaviours from trained clinicians, whose role it is to observe and report on the condition of individual patients.

6.4 Method

6.4.1 Pilot study

A pilot study informed the procedure of the main study. Specific aims were to:

1. Interview members of different professional groups and examine their responses.
2. Time the duration of interviews for the information of future participants.
3. Determine the questions to be asked.
4. Identify the most appropriate form of analysis.

6.4.2 Reflections on choice of settings

There were pragmatic reasons for carrying out the pilot study on the RRU. Firstly, because most patients there have complex problems, I knew that a substantial proportion would have communication and cognitive deficits and would meet the criteria for inclusion. Secondly, I had been responsible for co-ordinating development of the multi-disciplinary ICP for managing post-stroke shoulder pain there. I had already conducted an audit of the ICP process and was about to analyse a follow-up audit, so I had the authority to access the clinical records of patients known to have shoulder pain and to discuss their pain assessment with colleagues looking after them.

6.4.3 Ethical issues

This audit project had been set up with a wide brief, part of which was to investigate and put in train better ways of assessing pain in patients who found existing tools difficult to use. It had been funded by the North West Thames Regional Health Authority and was registered with the Trust's Research and Development system. At the time of registration, formal ethical permission was not required for the on-going development of processes designed to improve clinical practice and hence patient care. Members of the team employed on the RRU at the time knew about this project and were in full support of the investigative work that contributed to it. Had this study been undertaken in different circumstances, obtaining formal ethical approval for a study that would entail inviting staff members to participate in tape recorded interviews would have been essential. Such approval was, of course, obtained for the main study.

6.4.4 *Participants and procedure*

To limit bias from my close professional relationship with the five team members who had played a prominent part in the development of the ICP, and as other equally experienced staff were available for interview, I decided to exclude the former group. Six other members of the team, who were looking after two aphasic patients with shoulder pain, volunteered to participate in tape-recorded interviews. One doctor was interviewed about both patients and two physiotherapists, one occupational therapist, one staff nurse and one health care assistant were each interviewed once about the patient they knew best.

No pre-determined schedule of questions had been prepared for these seven exploratory interviews. To start with, interviewees were asked how they recognised shoulder pain in the named patient. Questions then centred on their recall of specific incidents in which patients' behaviours had led them to believe that they had a painful shoulder. Relevant details were probed for with the aim of eliciting clear, concise behavioural descriptions of pain episodes. Related issues were also followed according to their perceived contribution to the research topic. All interviews were transcribed verbatim and examined in depth.

6.4.5 *Findings*

6.4.5.1 *The timing of interviews*

Volunteers had been consulted about their availability beforehand to avoid interviews being carried out under pressure of time. In each case, discussion continued until they could think of no more to say on the topic. Interview times ranged (to the nearest minute) from four to 16 minutes with a median time of seven minutes. It was concluded that it would not be unreasonable to ask hospital staff to agree to participate in interviews of this length.

6.4.5.2 *Examination of interview transcripts*

At the outset, the intention had been solely to classify pain behaviours by grouping them as units of coding under clearly defined labels, thus following the conventional method for content analysis. It was expected that some would be similar to those identified in previous studies of pain behaviour and that these could be compared. To start with, sections of the transcripts that described behaviours suggestive of pain were highlighted. These were copied and pasted into a single document and similar behaviours were grouped under seven thematic headings:

1. Verbal and/or vocal responses
2. Gestures of head and/or hands
3. Facial expressions
4. Holds/protects/touches arm
5. Tenses arm/body
6. Pulls away from being moved
7. Restlessness

On further scrutiny, though, it became clear that generating a list of behaviours was only one part of the picture and that there were other important questions to pursue that could not be answered from this small sample of interviews. Firstly, might there be a 'typical' hierarchy of behaviours that could indicate changes in pain intensity? If so, this could contribute to the design of a systematic behavioural assessment tool for post-stroke shoulder pain.

In addition, to be of any practical use, understanding these behaviours and acting appropriately to lessen them required consideration of when pain was most likely to be evoked. This gave rise to the second question. In which contexts were pain behaviours observed? To elucidate this could be relevant for educational purposes, so four different contexts in which shoulder pain was observed to occur were identified:

1. During routine clinical examination
2. When exercising in therapy sessions
3. When seen to be awkwardly positioned
4. During personal care activities

Finally, interaction with the patient to confirm the significance of their behaviour was also described by every member of staff. This appeared to be a crucial part of detecting pain and one that informed their clinical judgements and proxy reports, so warranted further investigation. Thus a third question was identified. What processes of reasoning were used to verify assumptions about pain?

6.4.5.3 Informing the analytical framework

Some issues arising from the questions posed above were complex and imprecise. It was realised that the analysis would need to be extended to do justice to them. A procedure for qualitative content analysis, developed by Mayring (1988) and described by Flick (1998c), finally informed the organisation and coding of data. In summary, this is a procedural model of text analysis in which several analytic units are first defined. The *'coding unit'* defines the smallest text element that can be analysed; in this case descriptors of pain behaviours. Once coded, behaviours could be clustered and tabulated (a) according to type and (b) in a hierarchy of intensity. The *'contextual unit'* defines the largest element in the text that can be categorised; descriptions of the circumstances and/or context in which behaviours were observed fitted this concept. The *'analytic unit'* defines which passages are consecutively analysed; in this case, the sequences of text that described the verification of assumptions about pain.

6.4.5.4 Methodological issues

Additional findings influenced the main study in various ways. In particular, differences in contact between patients and members of different professional groups showed the need for purposive sampling across both professions and settings. Aiming for maximum variation within the sample would increase the chance of obtaining a comprehensive account of pain behaviours and enhance understanding of the research topic, as evidenced by the following examples.

Firstly, different professionals observed discrete pain behaviours in different contexts. For instance, the physiotherapist noticed signs of pain while assisting with passive movements to maintain range in the upper limb. In contrast, the occupational therapist was particularly concerned with choosing a wheelchair arm rest that would allow the arm to be supported at rest in a pain-free position and had specifically noticed signs of discomfort when the arm was poorly positioned. Thus it was reasoned that including representatives from each professional group in the main study was essential.

Secondly, because introducing the ICP had raised the profile of shoulder pain on the RRU, some staff had developed sensitivity towards pain behaviours that might not have been typical of staff in less specialised units. For example, the doctor described how she routinely assessed each patient *'every two weeks according to the [ICP] protocol'* to determine the presence of shoulder pain, and was explicit in her recognition of pain behaviours. On the other hand, nursing staff had been schooled in the need to avoid causing pain during personal care activities. The staff nurse was aware that shoulder pain was a problem, was particularly careful when handling and moving patients and consequently observed few pain behaviours. As she said, *'I know he's on the shoulder protocol, so I'm not doing anything to that arm.'* These findings suggested that conducting the main study on the RRU might fail to reveal what staff in less specialised settings would recognise as shoulder pain behaviours. It was therefore decided to expand the investigation to include an acute unit in a different hospital altogether.

6.5 Main study

6.5.1 Setting and participants

A district general hospital in a different health region from the RRU was approached for the main study. It has a Stroke Unit through which all stroke patients pass before decisions are made about their longer term destination. As their details are entered into a stroke register, a consecutive cohort of in-patients with a diagnosis of stroke could be identified and regularly screened for shoulder pain. The staff that cared for those with pain could then be invited to participate in the interview study.

On average, one person per day is admitted with a stroke, but only about 40% remain as in-patients for over two weeks. The rest either die or go home. It was estimated that over the course of four months, up to 50 patients could be screened. To allow for follow-up until discharge, at least six months would be required for data collection. Based on findings in the literature, it was surmised that about half of these patients would develop shoulder pain at some point. Clearly, some would not have communication deficits and others would not wish to participate in the study. However, if ten patients with pain were to be recruited and five members of staff were to be interviewed for each one, fifty accounts of pain behaviours could be analysed, a number in line with other similar studies (Kemppainen, 2000; McGrath et al., 1998).

Meetings to discuss the proposal were arranged with the Lead Consultant for Stroke and the Clinical Nurse Manager. Full support was given, so a detailed proposal was prepared. This included a letter of invitation to participate signed by the Consultant (Appendix E), an information sheet (Appendix F) and consent/assent form (Appendix

G) for stroke patients and/or their relatives, together with an information sheet (Appendix H) and consent form (Appendix I) for hospital staff. Copies were sent to the Consultant and Clinical Nurse Manager for feedback and sanction to proceed with an application for ethical consent to undertake the study.

6.5.2 Ethical issues

Submissions were made to the North and Mid Hampshire Local Research Ethics Committee (LREC) and to the Southampton University Psychology Department Research Ethics Committee. An invitation to attend the North and Mid Hampshire LREC meeting to answer some questions was accepted. Because pain behaviours from stroke patients with cognitive and communication deficits were specifically being investigated, it was clear that assent from relatives would be needed in cases where patients were unable to give informed consent themselves. Although this had been addressed in the information leaflet and consent form, members of the Ethics Committee wanted to make certain that the difference between assent and consent could be explained to relatives if necessary.

Approval was given for the study to proceed (Appendix J), whereupon further mandatory conditions were complied with. Professional indemnity insurance cover was obtained from the University of Southampton Finance Department. Then, to comply with current research governance regulations, the study was registered with the Research and Development Officer at the Hospital. The Data Protection Officer was notified and relevant forms completed. Arrangements for provision of an honorary contract for the duration of the study were made and access to the computerised patient database was granted.

6.5.3 Practical considerations

Some practical and administrative issues were addressed. To publicise the study, a series of presentations were given about it to staff on the Stroke Unit and to departmental therapists. Information sheets were distributed and questions answered on these occasions. Several visits were subsequently made to the Stroke Unit to meet the administrative, nursing and therapy staff, to agree on the most efficient procedure for obtaining details of potential participants and to investigate a suitable location for conducting interviews. More copies of information sheets were left on the ward.

6.5.4 Procedure

This is detailed in the flowchart below. Patients were eligible for inclusion if the medical team had confirmed a diagnosis of stroke and if they were still in hospital two weeks after onset and likely to stay for another week. Senior nursing staff and doctors made decisions as to who would be appropriate to approach. Patients were excluded if they were likely to die, or if they were too ill for an approach to be made to them or their relatives. They were also excluded if they were physically able and had regained full use of their affected arm (the few who fell into this category tended to be those with multi-infarct dementia or confusion, who remained in hospital for social reasons).

A consecutive cohort of stroke patients admitted between 01.09.02 and 01.01.03 was identified through the stroke register

↓

Senior medical and/or nursing staff were consulted about their suitability for an approach

↓

Two weeks after admission, a letter and information sheet was given to eligible patients or their relatives by their named nurse

↓

Patients or relatives who agreed to participate were met and a time was arranged to explain the study

↓

Consenting patients were given an appointment for an initial assessment

↓

On assessment, demographic information was obtained, a physical examination was carried out and patients completed the AbilityQ and ShoulderQ

↓

Once patients had been identified as having shoulder pain, members of their rehabilitation team were invited to participate in an interview

↓

Patients without shoulder pain were screened for shoulder pain every two weeks during their stay

Figure 6: Flowchart showing the procedure followed

Their named nurse gave patients who met these criteria (or their relatives) the letter of introduction and an information sheet. On the next mutually convenient day, those who agreed were introduced to me, whereupon I explained the study further and obtained informed consent/assent. An appointment was then made for an assessment within the next few days. This was documented in the nurses' diary to ensure that it would not conflict with any planned procedures or treatment sessions.

6.5.5 Reflections on identifying potential patient participants

In theory, consecutively admitted stroke patients were to have been screened for the presence of shoulder pain two weeks after their stroke and then every fortnight during their stay. However, in practice this did not turn out to be as simple as it sounds. Soon after the study began a shortage of general medical beds meant that several patients with conditions other than stroke were admitted to the Stroke Unit. This had the knock on effect of some subsequently admitted stroke patients becoming 'outliers' on other wards. Keeping abreast with this shifting population involved tracing patients being looked after by teams who had not previously been informed about the study.

Furthermore, identifying patients from the stroke register was complicated by uncertainty about their diagnosis. A specific problem that came to light early on was that the recently appointed ward clerk, who was responsible for updating the register, was confused by the system in place. Every patient suspected of having a stroke was referred for a CT scan and she was expected to extrapolate diagnostic information from the returned CT forms and enter this into the register. However, she didn't get round to doing this very often; partly because she was so busy but also because she was not familiar with some of the medical terminology used and couldn't always distinguish patients with a confirmed or probable stroke from those with other conditions. I discussed this with her and we wrote out a list of terms to place in the front of the register for her to refer to. This helped to some extent, but in the end I took to looking through the CT forms myself. Although it cannot, in truth, be claimed that every single patient with a stroke was identified, I believe that the majority was.

6.5.6 The protocol for examining patients for shoulder pain

This was derived from the ICP system in use on the RRU for identifying shoulder pain. After obtaining demographic details, together with the dates of stroke onset and admission to hospital, each recruited patient completed the AbilityQ (see Appendix K). This test is used to identify the individual's ability to respond to verbal questions and to use a numbered rating scale correctly. It therefore served as a screen, helping to separate patients with communication and cognitive problems from those without. It also acted as an indicator, pointing to whether responses to the ShoulderQ (see Appendix L; also Chapter 2, page 28) could be judged to be reliable and highlighting the type of help needed to complete it successfully.

These questionnaires were first presented in A4 format as they appear in the appendices. However, if patients had difficulty reading the questions, they were presented in large print with each question on a separate A5 sheet. Help was given as necessary; for instance the questions were read out or the boxes indicated were ticked if the patient had difficulty reading or using a pen. Care was taken not to influence the answers they gave. As relying solely on ShoulderQ responses might fail to identify the proportion of patients with pain, a physical examination was also carried out.

With the patient in sitting, the shoulder was palpated to determine any tenderness and moved passively through elevation, abduction, lateral and medial rotation to identify pain on movement. The Ritchie Articular Index (Bohannon & LeFort, 1986), a method of grading joint tenderness using a four-point scale of response to pain during a specific arm movement, was then used to rate pain on lateral rotation with the patient lying supine (Appendix M; also see Chapter 2, page 27). Pain was judged to be present if any one of three tests was positive:

1. If the patient answered 'yes' to questions about pain, whether by verbal response, gestural response or from their answers to questions on the ShoulderQ.
2. If palpation or passive movement elicited a vocal or facial response indicating pain.
3. If the patient scored one or more on the Ritchie Articular Index.

If the patient was found to be pain free on initial assessment, they were re-assessed at two weekly intervals during their stay in hospital to ensure that any with later onset pain could be included in the study.

6.5.7 Reflections on patient recruitment

Two problems affected recruitment. Firstly, more patients were discharged early to supported care at home and to two elderly care hospitals than had been indicated at the outset. To improve uptake, an extension to include patients at these hospitals was sought from the North and Mid Hampshire LREC and permission was subsequently granted. A second problem highlighted the difficulty of conducting health services research as an 'outsider'. I was required to make it clear on the information sheets that the study was being carried out as part of a PhD degree, so the research may have been seen as for my benefit alone. For example, the husband of one patient said he would like to help me with my PhD but thought his wife was too weak. Had I been employed as a 'legitimate' physiotherapist on the Stroke Unit with a clinical reason for assessing stroke patients early after onset, a request to carry out an additional more searching shoulder pain assessment than routine for research purposes might have been viewed differently.

Though slow at the outset, recruitment eventually improved and two patients from one of the elderly care hospitals agreed to participate. Both had been there for several weeks and were identified by staff caring for them as having shoulder pain. Two more patients were recruited from the RRU. Thus the final cohort consisted of patients from both acute and longer-term settings.

6.5.8 Staff interviews

Once stroke patients with shoulder pain had been identified, staff having regular close contact with them were invited to participate in an interview. They comprised health care assistants, nurses, physiotherapists, occupational therapists, therapy assistants and doctors. There were no explicit inclusion or exclusion criteria for staff, other than being familiar with the patient in question and a willingness to participate in a tape-recorded interview. The 34 who agreed were consulted about a convenient interview time. They gave written consent and were interviewed in a quiet room. To open the conversation they were asked, *'What signs have you noticed that suggest to you that [Name] has shoulder pain?'* Additional questions focused on the specific incidents described, issues identified in the pilot study and any new insights generated by the interviewee.

6.5.9 Procedure for managing and analysing data

Every critical incident interview was transcribed verbatim. Individuals and hospital settings were anonymised. Transcripts were read several times and annotated with marginal notes that indicated descriptions of pain behaviours (*coding units*) and their context (*contextual units*). A coding framework was constructed in which behaviours and contexts were grouped under six broad categories and labelled. Each category was defined and further sub-divided into items reflecting variation within each one. Items were described and illustrated with examples from staff interviews.

Two independent professionals, a research psychologist and a research nurse, evaluated the inter-rater reliability of the coding framework. Six transcripts were intentionally chosen to reflect the spread of staff and settings. This ensured that the full range of behaviours and contexts coded would be scrutinised. Each rater coded the transcripts independently according to definitions in the coding framework (see table 10, page 143). Their codings were then compared and scored by the researcher as follows:

- 1 was scored if both raters agreed on a behaviour or context.
- 0 was scored if raters disagreed on a behaviour or context.
- 0 was scored where one rater coded behaviours or contexts not coded by the other.

Because there were a small number of units rated at a nominal level for their presence alone, percentage agreement was chosen as the most appropriate, and the most commonly cited, measure of inter-rater agreement for these circumstances (Boyatzis, 1998). This was calculated by dividing the number of times both raters agreed by the number of possible instances of coding and multiplying by 100.

Coded pain behaviours were collated to produce a perceived behavioural repertoire for each patient. Thereafter, the hierarchy of behaviours presumed by staff to indicate increasing pain intensity was compared within and between individual patients.

The *analytic units*; that is sequences of text describing the reasoning that staff used to determine whether behaviours were due to shoulder pain as opposed to other problems, were complex and harder to code. Instead, they were marked and grouped under several broad headings. Extracts from interviews are presented in the results section to support the findings. Quotations are referenced by profession followed by interview number and line number. For example, 1.19 refers to interview 1 line 19. Italics are used to distinguish the interviewer's speech from that of the hospital staff.

6.6 Results

These are presented as follows:

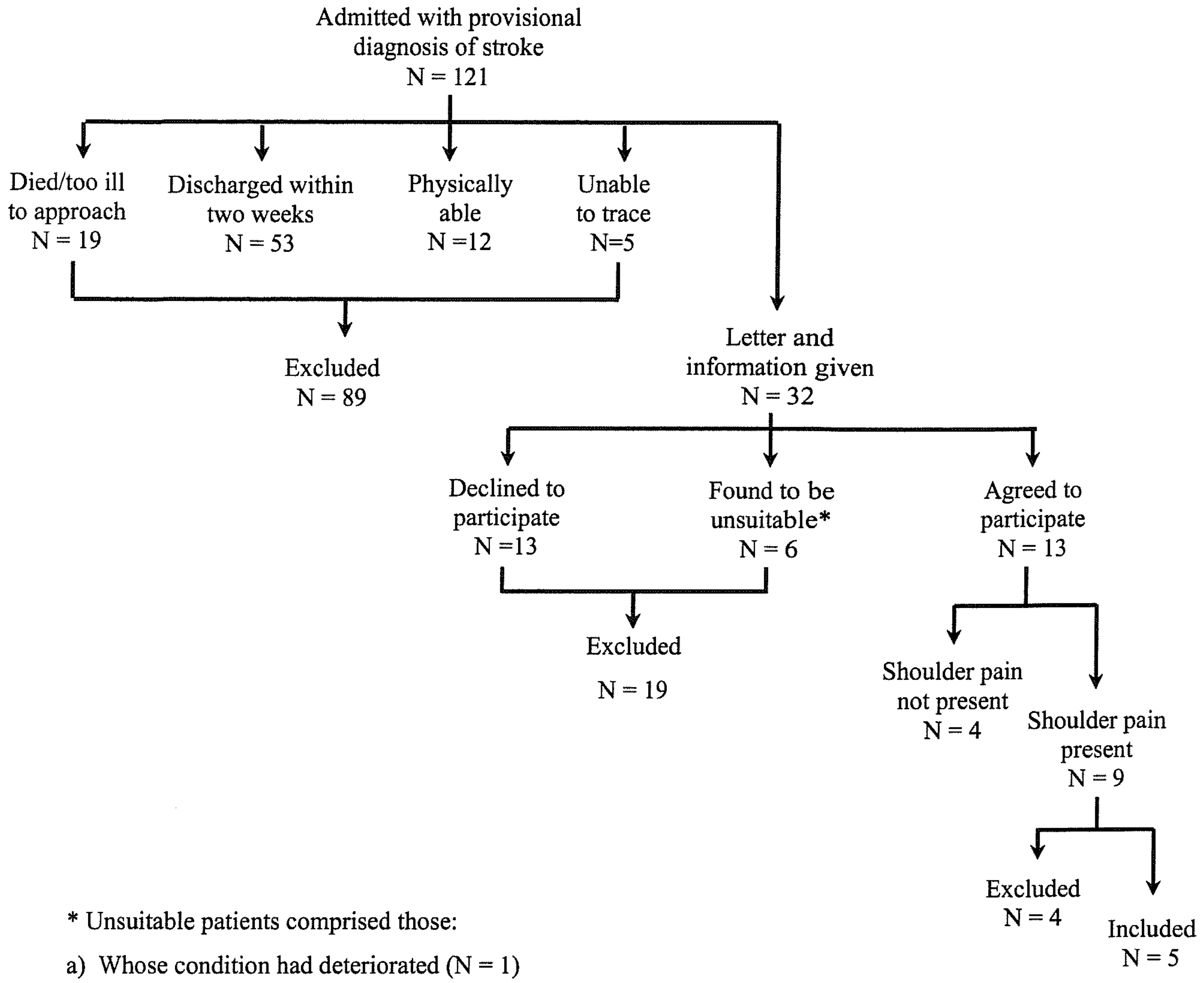
1. Patient recruitment and characteristics
2. Staff recruitment and characteristics
3. Analysis of findings
    a) Reliability of the coding framework
    b) Observed pain behaviours
    c) Pain behaviours indicating changes in intensity
    d) The context of pain behaviours
    e) Process of ascribing behaviours to shoulder pain

6.6.1 Patient recruitment

Stroke patients admitted to the Stroke Unit during a four-month period were screened for eligibility. A breakdown of these patients is given in Figure 7 (page 146).

Nine patients were identified to have shoulder pain. Among this group, four were able to give fluent verbal accounts of their pain and complete both the AbilityQ and ShoulderQ. They were excluded from further study and staff were not interviewed about this group.

This left five patients with communication and/or cognitive problems from the acute setting. This group was supplemented by two patients from the elderly care hospital and two from the RRU, all with communication and/or cognitive problems. Staff were interviewed about each of these nine patients in the main study.



* Unsuitable patients comprised those:

a) Whose condition had deteriorated (N = 1)
b) Who were found to be physically able (N = 3)
c) Who had no relatives able to assent (N = 2)

Figure 7: Breakdown of patient recruitment on the Stroke Unit

To ensure that findings were as inclusive as possible, and as the criteria for inclusion remained the same, interview data about the two RRU pilot study patients were pooled with data from the main study. This gave a final total of eleven patients, about whom 34 staff gave a total of 54 interviews. Table 7 (page 147) sets out the final distribution of recruited patients and staff.

Table 7:

Distribution of recruited patients and staff by setting

	Acute setting	Longer term settings		Total
	District general hospital	Elderly care hospital	Rehabilitation unit	
Patients recruited	5	2	4	**11**
Staff interviewed	16	5	13	**34**

6.6.2 Patient characteristics

The characteristics of included patients are shown in Table 8, which highlights the differences between those from acute and longer-term settings. The acute group was older and the length of time between stroke onset and inclusion in the study was shorter. Two in this group had developed shoulder pain some time before recruitment. One had been deemed unsuitable for an approach early after her stroke because it was thought she would die; her family assented to her inclusion three months later when her general condition improved. By this time she had severe shoulder pain. A second had sustained her stroke whilst on holiday in Canada and was admitted to the Stroke Unit on her return, six weeks after onset.

Table 8:

Characteristics of included patients by setting

	Acute setting (n=5)	Longer term settings (n=6)
Gender	2 male: 3 female	5 male: 1 female
Side of hemiplegia	3 right: 2 left	5 right: 1 left
Age (years)	Range 70-82; Median (IQR) 78 (73-81)	Range 43-78; Median (IQR) 68 (51-75)
Stroke onset to study (weeks)	Range 2-13; Median (IQR) 6 (3-10)	Range 7-45; Median (IQR) 20 (10-38)

To 'pass' both verbal and numeric domains of the AbilityQ, patients had to complete at least three out of the four verbal questions and all of the three numeric questions correctly (Turner-Stokes & Rusconi, 2003). Of the eleven patients, only two were able to do this. One other correctly completed three out of four verbal questions but was unable to understand the numeric scale. The remaining eight were unable to complete the AbilityQ, though six gave correct responses to the first two questions (testing the ability to correctly indicate 'yes' and 'no'), using words or gestures.

The two who passed the AbilityQ completed the ShoulderQ without assistance. Of the remaining nine, seven were able to indicate in some way that they had shoulder pain, for example by nodding their head or pointing to the shoulder when asked if they had pain. By using gesture to help explain ShoulderQ questions, two of this group were able to signal 'yes' or 'no' to questions asking if they had pain at rest, on movement or at night. However, they were unable to understand the numeric scale. Two patients appeared unable to understand or communicate anything using higher mental processing. Shoulder pain was determined from observation of their behaviour.

On physical examination, palpation around the shoulder joint and/or passive movement of the shoulder elicited either a vocal or facial expression indicative of pain in nine out of the eleven patients (82%). Scores on the Ritchie Articular Index (Bohannon & LeFort, 1986) are shown in Table 9.

Table 9:
Distribution of scores on the Ritchie Articular Index

Score	Description	Patients (N=11)	Percentage
0	Patient has no tenderness	2	18%
1	Patient complains of pain	6	55%
2	Patient complains of pain and winces	3	27%
3	Patient complains of pain, winces and withdraws	0	0%

6.6.3 Staff recruitment and characteristics

Thirty-four staff gave a total of 54 interviews. The number and diversity of staff interviewed about individual patients varied (see Table 10 below), as not all patients were having physiotherapy and occupational therapy. Also, the ratio of nursing and care staff to each patient was much higher than that of therapy and medical staff. Some staff were interviewed about more than one patient. One doctor and one care assistant declined to participate because they said they had not realised that the two patients in question had shoulder pain.

Table 10:
Numbers of staff interviewed in each professional group

Professional group	Numbers interviewed
Doctors	4
Occupational Therapists	4
Physiotherapists	6
Physiotherapy Assistants	2
Staff nurses	7
Care Assistants	11
TOTAL	34

Participants were asked for how long they had worked with stroke patients. The time ranged from four months to 27 years (median 5 years 6 months). Thus the sample included both inexperienced and experienced staff.

6.6.4 Analysis of findings

Five categories of pain behaviour were identified: *Vocalisations, non-verbal signals, facial expressions, body movement and activity.* A further category of *context* was added. As described in section 6.5.9 (see pages 143-144), a framework for coding pain behaviours and their context was compiled and is shown in Table 11 on page 150.

Table 11:

Final coding framework for behaviours perceived to indicate shoulder pain and for their context

Category label	Definition of category	Description of component items	Examples from staff interviews
1 Vocalisation	A verbal or vocal utterance used to convey information about pain.	a) A specific word or words suggesting or confirming pain	a) She'll say, 'That hurts'
		b) Non-verbal articulations suggesting pain	b) He tends to go, 'Oooh'
		c) Other vocalisations suggesting pain and/or distress	c) She'll start to make a moaning sound
2 Non-vocal signal	A gesture or sign indicating presence or location of pain	a) Uses the hand to point to the affected arm or shoulder	a) He would point to his arm, his shoulder
		b) Touches or rubs the affected arm or shoulder	b) Sometimes he'll rub the area
		c) Looks towards the affected arm or shoulder	c) Gives an indication by looking at the shoulder
		d) Gestures in response to questioning	d) A nod, it was body language really
3 Facial expression	A change in facial appearance that indicates presence or absence of pain	a) A change in or around the eyes suggesting pain	a) She has a frown between her eyes
		b) A change in or around the mouth suggesting pain	b) She brings her bottom lip up over her top lip
		c) A widespread change in the face suggesting pain	c) He started grimacing
		d) A change in the face suggesting relief from pain	d) His face relaxed
4 Body movement	A posture or movement of the body serving to protect the arm or shoulder	a) Uses the unaffected arm to hold or guard the affected arm	a) He cradles his arm
		b) Tenses the body to resist movement [1]	b) Fixes with the right arm
		c) Grabs the arm or pulls it back to prevent movement	c) He will pull his arm away from you
		d) Actively seeks to re-position the arm to restore comfort [2]	d) She's looked for a pillow
5 Activity	A general change in body activity indicating presence or absence of pain	a) Increased movement of the whole body suggesting discomfort	a) Her whole body starts to writhe
		b) A lessening in movement of the body suggesting relief from discomfort	b) She'll just be sat there
6 Context	Specific circumstances of observed pain behaviours	a) During clinical examination	a) On examination she's very tender
		b) When exercising the arm or lifting it up [3]	b) You've got to lift up her arm to put the sling on
		c) When the patient is found to be awkwardly positioned	c) Shows it in her face when she lies on it
		d) Turning, transferring or positioning the patient	d) Mainly when she's being turned in bed
		e) While assisting with personal care activities	e) Providing personal care … putting clothes on

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[1] The previous wording of item 4b was: Tenses the body to resist being moved.

[2] The previous wording of item 4d was: Initiates positioning of the arm to restore comfort.

[3] Two former items: 6b) When exercising in general during therapy sessions and 6c) Specifically when lifting the arm up, were amalgamated to form the new item 6b.

6.6.4.1 Reliability of the coding framework

To evaluate its reliability, agreement between the two independent raters was calculated. Ratios between matched, mismatched and supplementary codes and the times coding was possible is shown with percentage agreement in Table 12 below.

Table 12:
Inter-rater agreement of coding categories

	Matched codes	Mismatched codes	Supplementary codes	Total
Times coding occurred / Times coding was possible	50/77	7/77	20/77	77/77
Percentage agreement	65%	9%	26%	100%

Agreement of 70% and over is generally regarded as acceptable (Boyatzis, 1998). This level was not initially reached for matched codes. Examination of raw data revealed that in the seven cases where coding was mismatched, disagreement had occurred between items in *facial expression, body movement* and *context* categories. Supplementary coding mostly occurred because one rater had coded the same behaviour more than once during a conversation in which it was repeated.

A meeting was arranged with the two raters to resolve these differences. The difficulty of converting subjective descriptions into coherent unambiguous codes was discussed. Questions of ambiguity in *body movement* and *context* categories were resolved through consensus and led to changes which are indicated in the footnotes to Table 11. It was suggested that the *activity* category might include an item representing restlessness/agitation, as this had featured in one transcript referring to a patient who threw her bedclothes off to draw attention to her discomfort. It was decided that this was not sufficiently different from item 5a (increased movement of the whole body suggesting discomfort) to warrant inclusion.

Within the *facial expression* category, items 3a) 3b) and 3c) had been deliberately phrased in lay terms to reflect variations described by interviewees. However, semantic questions were raised in connection with terms such as *wince* and *grimace,* which were used by some interviewees and could have referred to the eyes or mouth only, or to the whole face. It was finally resolved to keep the status quo but to define *wince* and *grimace* operationally in any future work as indicating overall facial expressions of pain, unless qualified otherwise. This concurs with others (Ahles et al., 1990; Cinciripini & Floreen, 1983; McDaniel et al., 1986; McGrath et al., 1998).

Finally, the usefulness of including 'negative' pain behaviours; that is, changes in behaviour suggesting relief from pain was discussed. As will be evident from examples given later in this chapter, the ability to recognise behaviours indicative of pain as well as noting their absence was critical to the process of reasoning that some staff used to verify their suspicions concerning pain, so there were good reasons for retaining these items.

6.6.4.2 Observed pain behaviours

Pain behaviours detected by staff were sometimes initiated by patients, thus serving the purpose of alerting others to their pain. They were also sometimes elicited by staff while seeking to confirm their reading of patients' pain. As shown in Table 11, a variety was identified. Those classified as *vocalisations*, *facial expressions* and *activity* were potentially generic; that is they could have indicated pain in any area of the body. They could also have been misleading, as suggested by the earlier analysis of videotaped shoulder assessments carried out by physiotherapists. In contrast, behaviours in the *non-vocal signal* and *body movement* categories were more specific to the shoulder or upper arm and less likely to be misinterpreted. Nonetheless, several members of staff commented on the difficulty of being sure that behaviour was directed at the shoulder, as opposed to another area of the body, and were cautious when attributing signs. In other cases, it was only on questioning that interviewees agreed that an initial assumption might have been wrong, and that apparent pain behaviours could have been evoked by something else.

Though there was some consistency in behaviours observed by staff in individual patients, there was also divergence. This was not surprising as the amount and type of contact that members of different professions had with patients varied (this reinforced the pattern noted in the pilot study). However, staff may also have differed in their sensitivity to behaviours, a difficult issue to discern and one that is revisited in the next section. A few mentioned sharing information about shoulder pain with other members of the team, but no clear picture emerged as to the extent of this communication and whether it was documented in any way.

6.6.4.3 Pain behaviours indicating changes in intensity

Structured instruments for rating the intensity of pain behaviours were not used. A handful of those who said they could discriminate gave proxy estimates of pain intensity on a 0-10 scale but others were unwilling to commit themselves to more than three crude grades, generally in terms of mild, moderate and severe.

More than half of the interviewees said they could not judge intensities of pain shown by the patient in question. This could have been because they had infrequent contact with him/her. Alternatively, the patient may only have had mild pain at the time they were usually seen. Then again, the extract below suggests another reason; that the personality or the emotional state of the patient could confound making this kind of judgement.

> *Do you think you could tell from the way he behaves whether his pain was mild or severe?*
>
> Not really. The only time I would think, oh perhaps he is in pain, is because of his mood because he gets very abusive. That's the only way that I would really know that he's in any distress or whatever.
>
> *What about facial expressions?*
>
> Mm, not really, he's grumpy all the time. Care Assistant; 17.26-34

On the other hand, it could be that this care assistant lacked the sensitivity, knowledge or experience to detect subtle signs of pain. In support of this suggestion, it was interesting to note that a second care assistant looking after this man had noticed him wincing and grimacing when his arm was being moved to get hoist slings in place, and pulling away when being rolled. On other occasions he was seen to cry out and become abusive, which the second care assistant interpreted as conveying increased pain.

Despite these uncertainties, when interview extracts describing behaviours perceived by staff to indicate changes in intensity were collated for each patient, some patterns began to emerge. Table 13 (page 154) shows how behaviours observed in one patient were divided into two broad intensity groupings based on how individual staff interpreted their meaning.

Table 13:

Behaviours perceived by staff to indicate differences in pain intensity in patient 8

Staff member	Less intense	More intense
Care assistant	Relaxes, becomes calmer and opens her eyes on adjusting arm position.	Increased facial expression, moaning begins and gets more intense. Unsettled.
Care assistant	Makes less noise.	Makes a lot of noise – whining. Brings bottom lip up over top lip.
Care assistant	Moans, pulls a face, groans. Becomes quiet after analgesia	Pushes more. Cries out over a long time.
Consultant physician	Twinge of the mouth/grimace.	Increased agitation when arm moved into external rotation, whole body writhes.
Junior doctor	Grimaces, calls out	More agitated, more vocal. Increased facial expression.
Staff nurse	Less of a frown, noise more of a grumble than a groan. Relaxes when in a 'good position.'	Deeper frown, louder noise, looks more distressed. Signs almost constant.
Staff nurse	Grimaces/crumples her face.	Calls out 'Oooh', goes on calling out for longer and voice becomes higher.

Having grouped behaviours in this way for each patient, hierarchies of *vocalisation, facial expression, body movement* and *activity* were extracted and listed to explore similarities and differences across all patients. An increase in intensity was commonly cited in comparative terms; that is as more or less than 'normal'. The following extract illustrates this:

> *Can you discriminate in terms of pain intensity with respect to the way she behaves?*
>
> Well, her level of agitation, certainly she seems more vocal the more painful it gets; she's generally very quiet and doesn't make much noise at all. Whenever you start to move that side, facial expression, she doesn't have much facial expression normally, that increases as well as her vocalisation. Doctor; 34.19-25

Comparisons were made in various ways. As pain was perceived to increase, the following changes were noticed in general terms:

- Patients reacted earlier during a movement or intervention.
- Their reaction to being moved became stronger and more marked.
- Behaviours were seen more frequently.
- Behaviours lasted for longer periods of time.
- A number of behaviours were seen in combination.

In more specific terms:

- An indrawn breath developed into a vocalisation such as 'ow'.
- A vocalisation, such as a moan, grew into a cry or a shout.
- Facial expressions progressed from a slight flinch to the whole face screwing up.
- A slight resistance to movement changed into pulling the arm back.
- The whole body changed from being relaxed to becoming tense or agitated.

6.6.4.4 The context of pain behaviours

Pain behaviours were commonly observed, indeed were specifically looked for, during the course of a structured clinical assessment by doctors and therapists. Such assessments tended to be carried out soon after the patient had been admitted to hospital and thereafter at variable intervals. Specific techniques, such as palpation or passive movement of the shoulder, were used to investigate pain at rest and on movement.

In an everyday clinical context, most pain behaviours were noticed when helping with transfers, personal care activities, during therapy sessions, or when happening to pass by a patient who had got into an awkward position and looked uncomfortable. The following extract serves to illustrate the simple association that many staff made between observed pain behaviours and physical care.

> *What signs does he give you that he's got shoulder pain?*
>
> The way he cradles his arm first of all, he won't let you go to touch any part of his arm. He will pull his arm away from you and cradle it. More obvious ones are that he will voice, 'Oh don't', as in, he can't form the words but he'll, it's quite clear that it's, 'Get off, don't touch, that hurts.'
>
> *And that's when you're doing what sort of thing?*

> That's normally with moving, as in from chair to commode, commode to chair, chair to bed, bed to chair.
>
> *Right.*
>
> Putting in the arm support, I think it is the Bexhill which is quite difficult to put in because you have to lift the arm right up to hook it into the slot. He used to find that quite painful. And dressing, when I'm just doing the top half. Care Assistant; 7.2-16

6.6.4.5 Process of ascribing behaviours to shoulder pain

Having observed behaviour suggestive of pain, as shown by the example above, there appeared to be differences in what happened next. On the one hand, some staff assumed a simple link between the observed behaviour and pain and left it at that. Others were more searching. Having made the link, they went on to confirm their hunch through questioning, or by a process of elimination, to see whether the behaviour changed as a result of intervention. Exploring a behavioural sequence; that is a behaviour initiated by the patient followed by one or more elicited by the health professional, informed their beliefs about whether the patient had shoulder pain as opposed to another problem, for instance wanting their clothing straightened out. This process of verification played a crucial part in the process of detection that the more perceptive health professionals employed. The behaviours that individual patients were noted to use when conveying information about shoulder pain to staff are presented in Table 14 (page 157). This distinguishes between the use of discernible verbal or vocal language and the use of body language or gesture.

Table 14:
Behaviours observed by staff in response to questions about pain (N=11)

Patient ID	Verbal/vocal behaviour	Gestural behaviour
1	'Yes/no'	Shakes head and/or hand Points to single word - pain
2	'Yes/no'	Gestures - a hand wiggle Nods head
3	'Mm'	Points to shoulder and down arm
4	Verbal responses	None observed
5	Unresponsive	None observed
6	'Here' (looking at shoulder)	Points at shoulder
7	'Yes' (reliability uncertain)	None observed
8	Unresponsive	None observed
9	Yes/no	Nods/shakes head
10	Verbal responses	None observed
11	Sounds perceived to mean yes	Nods/shakes head

To exemplify the process of verification, the following passage shows how a staff nurse noticed a behaviour suggesting shoulder pain while changing a patient's feed, and went on to clarify her assumption by inviting a response to closed questions about pain, and then by adjusting his position to see if this would relieve the problem.

> *What signs have you noticed when you're looking after him that suggest to you that he might have a painful shoulder?*
>
> It's his body language and his facial expression mainly. When I've been on night duty and we were taking his PEG feed down we were interacting. He finds it difficult to verbally say what the problems were, so I was giving him short closed questions to try and establish what the problem was. I said to him, 'Are you in pain?' and it was, 'Yes', a nod, it was body language really.
>
> Mainly it was positioning. He wasn't very comfortable the position he was in so he was turned, re-positioned and then again, by asking lots of questions so that he could nod or shake his head, so he could give a suitable response, we managed to settle him and, well he slept for the rest of the night which indicated; cos I thought, well I'd change his position and then if he doesn't seem to settle, then you know, we'll see about pain relief, but when we went back to him we checked and he'd gone to sleep. So, I mean I tend to think that if somebody's in pain they don't tend to sleep. Staff nurse; 42.1-15

Other members of staff went one step further and described in great detail how they interacted with patients to stimulate responses to questions about shoulder pain. This next extract shows how a physiotherapist spent time teaching a method of communication that was appropriate for a patient with profound aphasia. She goes on to describe how he responded by using gesture to indicate the intensity of pain once this 'common language' had been established between them.

> *How do you recognise signs of pain?*
>
> I will orientate him to what I'm doing because he's got a hemianopia and a neglect, so I'll make certain that I've got his attention. I call his name so I've got eye contact, so he turns his head, and then I demonstrate what I'm going to do.
>
> So I've shown that I'm going to lift his arm either into flexion or abduction. And then I will say to him, 'If it hurts', and I kind of pull a face, so I kind of go, 'Ffffff' you know, use my facial gestures, 'Tell me'. And actually because we've always gone through that routine ever since he was first admitted, he kind of knows what the score is, he knows what to expect.
>
> And what I do is, I just take his arm up very gently and there'll be a slight grimace and I'll say, 'Is that painful'? And he'll indicate with his other hand. If it's just about on the edge of the pain he'll gesture with the other hand, it's you know, middling, but if it's a sharp pain, he'll 'Ffffff' with his face, his facial gestures will show me.
>
> And then I'll just put it down a little bit and say, 'Has it gone?' And he'll nod, whatever. So, I mean, that's really how we do it. Physiotherapist; 5.1-15

Other staff were equally conscious of the need to engage with patients to gain insight into their pain but went about it in very different ways. Whereas the physiotherapist adopted a structured approach, the care assistant, whose account is given below, was unable to give a factual account of the signs that, for him, determined the presence of pain in this severely aphasic unresponsive patient, or even to engage with her in a process of direct communication. He referred to having a 'sixth sense' that came with regular contact and sensitivity to subtle behavioural cues.

> It does depend on body language. Even patients that can't communicate, because we work so closely with them, you do pick up their personality. You pick up just their general being and then you slowly get to know what's good and what isn't good you know, whether it be facial expressions or body movements, but it's so difficult, like you say, to put into words.

> I could talk to somebody about [Name], she could be in the room and I could tell you she's in pain but the other person would say she looks fine because it's not only working with the patients, it's actually bonding with them and actually becoming part of their life. Care Assistant; 15. 67-75

Meaningful interaction between staff and patients such as this one was complicated, not only by the difficulty some had in communicating verbally, but by the extent of cognitive deficits, such as neglect. This was commented on by nurses and therapists alike when explaining why patients could not show them where the pain was on their own body. Two were profoundly impaired and unable to understand or respond to questions of any kind (one was the patient referred to the above extract). In contrast, two others had sufficient use of language to give verbal responses to questions about pain; they were not seen to use gestures as an additional way of conveying information.

Being observant to pain behaviour sometimes led staff to conclude that a patient was concealing pain. For example, one patient with sufficient command of language to communicate about pain said nothing about it, though she affirmed that her shoulder hurt when questioned. It had been clear to the occupational therapist who arrived to help her get washed and dressed that she was in pain because of her facial expression and the fact that her arm had got caught underneath her and had pulled her shoulder into an awkward position. She indicated that she had not asked for help because the staff were busy and she didn't want to bother them.

Though other patients could respond to simple questions, there was some disagreement between staff as to how reliable two of them were. This group also used gestures of the head or hand to convey agreement or disagreement. One patient used gesture to point at his shoulder but did not give yes/no responses to questions. The inability to point to the shoulder to indicate the location of pain was remarked on for six patients.

6.7 Discussion

This study identified behaviours believed by health professionals to indicate shoulder pain in a group of stroke patients with communication deficits. These behaviours were clustered into categories and arranged in hierarchies of intensity. The contexts in which they were noted to occur were also tabulated and the processes of reasoning that staff used to confirm their assumptions about pain were outlined.

Before discussing the results, it should be emphasised that though this study revealed some new information about the nature and detection of shoulder pain behaviours, it was limited in scope. It would be unwise to claim that the findings could be generalised to the wider population of either stroke patients or health professionals at this stage. But importantly, some clear foundations for future research into this poorly understood field have been laid. Recommendations for action will be made in the final chapter of this thesis in the light of findings from the other two studies. For now, the strengths and limitations of the methodology in fulfilling the study aims will be reviewed. The findings will then be discussed in relation to previous research and to detecting pain in clinical settings.

6.7.1 Evaluation of the critical incident interview technique

The two cardinal principles of the critical incident technique are firstly, that it should be used to pinpoint *'factual information about behaviour'*, as opposed to opinions or general impressions and secondly, that reporting should be limited to behaviours which make a *'significant contribution to the activity'* under investigation (Flanagan, 1954). Both were fundamental to the aims of this study; that is to elucidate shoulder pain behaviours by obtaining factual information about them for teaching purposes and to inform the development of an assessment for stroke patients unable to self-report.

Flanagan (1954) maintains that the extent to which a reported observation can be accepted as fact depends on whether a number of independent qualified observers agree with it. Moreover, that once an agreed classification system has been devised for the observed behaviours, a degree of objectivity can be achieved. Thus the point of applying this technique to non-specific incidents, such as the pain behaviours observed in this study, was that a systematic collection of described behaviours could be pooled and synthesised to generate objective definitions of them. These can now be subjected to further validation by consensus. The method makes efficient use of time and, as Cox, Bergen, & Norman (1993) remark, limits expenditure of effort on irrelevant discussion. Though supplementary data were also acquired, the technique was found to be particularly suited to gathering multiple concise accounts of pain behaviours, together with information about their context, from busy health professionals in the clinical situation.

However, using this method in a time-limited study meant accepting a trade off between the quantity and richness of obtainable data; that is, in restricting questions to matters of fact, the topic may have been explored in insufficient detail. A more searching inquiry might have provided greater insights into health professionals' background knowledge of shoulder pain. This could have explained whether the sensitivity that some showed in attributing behaviours to it was a product of their education and training, or simply an intuitive process based on common sense. An additional gap in knowledge that was not filled by this study was the extent to which health professionals shared knowledge of shoulder pain behaviours among their colleagues during handovers and team meetings.

6.7.2 Limitations of the study in general

Although the critical incident technique per se was successfully piloted, the actual procedure of the main study was beset by a number of problems. Some might have been averted had it been piloted in the acute setting instead of on the RRU, where patients stay for several months and are relatively stable as regards their general health. Identifying patients with shoulder pain on the Stroke Unit was less successful than expected at the outset, partly because so many were discharged early to supported care at home and to other hospitals, but also because of the high proportion (40%) who did not wish to participate. The more severely affected patients tended to be bed bound with concurrent medical problems or complications. Though this was the very group most likely to develop shoulder pain, several patients (or relatives on their behalf), who were deemed suitable for an approach by the medical team, declined, so estimating the incidence of shoulder pain on the basis of the criteria I had defined was impossible.

Despite extending the study to another setting, the total number of patients recruited in the time available was fewer than hoped for so interview transcripts from the pilot study were combined with those from the main study for analysis. This could be seen as a limitation, but it is argued that the method remained the same and the final sample of patients and staff had greater diversity as a consequence, which some would see as a strength (Kemppainen, 2000).

Staff were only interviewed once in the course of patients' recovery period. It was therefore impossible to determine whether individuals might have displayed different behaviours during acute and chronic episodes of pain. A longitudinal study might have uncovered a wider spectrum of individual behaviours, but would have required a considerably greater investment in time than was available for this study.

6.7.3 Comparison of pain behaviours with other studies

As detailed in chapter 3 (pages 51-57), most previous research into observable pain behaviours has been targeted towards two distinct groups of individuals. In the general population, specific behaviours characteristic of defined pathologies where pain is often chronic; notably back pain or arthritis of various kinds, have been identified. In contrast, generic behaviours that could indicate any kind of pain have been determined in people with cognitive and/or communicative deficits. This study crossed the boundary between these groups by investigating specific behaviours characteristic of shoulder pain but doing so in people with communication deficits.

Nevertheless, some pain behaviours appear to be universal. Certain vocal and/or verbal expressions are well established indicators of pain and the findings in this study reinforced this. Items spanned the full range from specific recognisable words to shouting out and crying. There were strong similarities between them and those listed in assessments of pain behaviour for people with various kinds of chronic pain but without neurological deficits (Philips & Jahanshahi, 1986; Richards et al., 1982), non-verbal cognitively impaired children (Breau et al., 2000; McGrath et al., 1998) and non-verbal elderly people (Simons & Malabar, 1995).

Although particular facial actions are also common indicators of pain (Prkachin & Mercer, 1989), discriminating between the fleeting facial expressions that can embody personality traits and emotions as well as pain has been shown to be problematic (Williams, 2002). In this study, facial expressions were coded using lay terms to encompass the wide range of descriptors, both objective and subjective, that interviewees used. As well as describing a change in the whole face, exemplified by the term grimace, a number separated out expressions of the eyes and mouth, most notably when describing slight behaviours suggestive of mild pain. This distinction was also made by McGrath et al. (1998). The four primary actions that suggest a universal facial expression of pain; specifically, brow lowering, tightening and closing of the eye lids, nose wrinkling and upper lip raising (Prkachin, 1992), were not detailed by participants in this study, which would endorse the view of Solomon et al. (1997) that they are too precise for routine clinical practice.

Some categories of behaviour previously determined in individuals with cognitive and/or communicative deficits were not identified in this group. These included physiological signs, for example pallor or perspiring that could imply a serious injury, and indicators of a change in conscious state, such as drowsiness or disorientation, which could imply a systemic illness (Simons & Malabar, 1995; Weiner et al., 1999; Zwakhalen, van Dongen, Hamers, & Huijer Abu-Saad, 2004). Likewise, social behaviours, for instance avoidance of social activities (Philips & Jahanshahi, 1986; Vlaeyen, van Eek, Groenman, & Schuerman, 1987) were not mentioned. As there was little opportunity for patients to engage in social activities in these hospital settings this was not surprising. Changes in personality, such as becoming withdrawn (McGrath et al., 1998), although alluded to, were generally regarded as too ambiguous to be used as indicators of shoulder pain.

A significant difference between this study and others was the way non-vocal signals and gestures were classified. These elicited behaviours demonstrated the interactive nature of pain communication. In contrast, equivalent behaviours described in the literature appear only to have been observed. For instance, the example given by McGrath et al. (1998) for their item: Gestures to or touches part of the body that hurts, was: *'He seemed to pick and rub at his ear a lot'*. In this study, gestures that indicated information about pain included using the unaffected hand to point to the affected arm or shoulder and a nod of the head in response to questioning. This finding probably reflects the more detailed procedural model of text analysis used in this study, which went beyond the coding of pain behaviours and their context to examine modes of communication.

The body movement items cited by other authors have greater equivalence to the activity descriptors defined in this study, being largely non-specific. For instance, *'relaxed and awake'* (Simons & Malabar, 1995) and *'stiff, spastic, tense, rigid'* (McGrath et al., 1998). In contrast, the body movement items identified in this study were specifically directed towards the affected arm and were often identified during one-to-one contact. This concurs with Zwakhalen et al. (2004), who extrapolated the pain indicators perceived to be most important to nurses when diagnosing pain in people with severe and profound intellectual disability. The highest scoring indicators included behaviours observed *'during manipulation'* which suggest that they too were evoked as opposed to spontaneous behaviours. They go on to state that in determining pain, nurses seem to rely on behaviours relating to the situation in which they occur, as was found in this study.

Identifying specific activities most likely to elicit defined pain behaviours is useful, not only because this could suggest cause and effect, but also because a decrease in the frequency or strength of pain behaviour during an activity could be an important therapeutic outcome (Bohannon & LeFort, 1986). A series of active, passive and accessory shoulder movements, together with lifting the arm, have been identified as likely to induce pain behaviours in people with shoulder complaints in general (Prkachin & Mercer, 1989). However, the everyday activities that elicit shoulder pain behaviours in stroke patients have not been identified before.

6.7.4 Hierarchies of pain intensity

Fewer than half of the health professionals interviewed were confident of their ability to recognise differences in pain intensity from observed behaviours. It is not clear what the difference was between them and the majority who said they could not, but it would be worth investigating this further. It has been shown that physiotherapy and occupational therapy students can be trained to develop greater sensitivity towards subtle facial expressions associated with shoulder pain (Solomon et al., 1997). This implies that staff awareness of signs of pain in stroke patients could be improved, as could determining levels of pain intensity. On the other hand, in a study investigating facial expressions of pain in elderly patients with severe dementia, though nurses and medical students could accurately detect the presence of pain from videotaped observations of facial expressions between 80% and 90% of the time, they were not able to determine its intensity (Manfredi, Breuer, Meier, & Libow, 2003). However, these findings are unlikely to reflect clinical practice. It was declared in the study reported here that familiarity with a patient plays a significant part in developing sensitivity towards subtle signs of pain. Furthermore, clustering signs over and above facial expression may also be significant in judging pain intensity (Parke, 1998). Taken together, these findings support the feasibility of developing a behavioural intensity scale for post-stroke shoulder pain, though staff may need training to use it reliably.

6.7.5 Processes of detection

The decision to analyse the sequences of text that described the verification of assumptions about pain was provoked by reviewing the pilot study transcripts and noting how important this was to the validity of findings. A further theoretical influence came from accepting that pain communication is an interactive process. Though evidence of excellence in the way shoulder pain was detected in patients was shown by some accounts, apparent shortcomings were highlighted by others. The care and attention that many staff described exercising did not appear to be characteristic of particular professional groups. There were sensitive and less sensitive members across them all. Some health professionals compared perceived pain behaviour with 'normal' behaviour and others described how they went to considerable lengths to confirm a clue, using direct questioning about pain, together with gestures, to get their message across and encourage patients to respond if they could. Others seemed less inclined to query behaviours indicative of pain, though they noticed them nevertheless. Then again, a few used intuition; they realised there was a problem and responded appropriately, even though they could not be precise about the objective signs that led to this belief. Benner & Tanner (1897) define intuition as '*understanding without a rationale*' and in line with others (Orme & Maggs, 1993; Rew, 1988), describe how expert nurses use it alongside the analytic reasoning that comes from skilled observation and knowledge of the patient to make clinical judgements about patients in their care.

This finding goes some way towards counteracting the criticism levelled by focus group participants that many staff were oblivious to post-stroke shoulder pain, although no firm conclusions can be drawn either way. It could be that patients sometimes wrongly assume ignorance on the part of staff because they don't raise the subject. On the other hand, patients themselves conceal pain for a variety of reasons. To investigate differences between perceived and actual lack of awareness of the presence and nature of shoulder pain, contemporaneous interviews would need to be carried out with patients and the staff caring for them.

Two health professionals declined to participate in this study despite having responsibility for the two patients in question; in both cases known by other staff to have shoulder pain. The doctor explained that she would expect to be alerted to this kind of problem by nursing staff and had not been in this case. The care assistant said that there would be no point in being interviewed as she did not know the patient very well and wasn't aware that he had pain. This is a matter for concern. Were this proportion (6% of the sample) to reflect the situation in other settings, an unacceptably high number of staff may be unaware that the stroke patients they are looking after have shoulder pain. This also raises the question of how information about patients' pain passes between members of the medical team as a whole. In the normal way, it might be expected that it would be communicated during ward rounds or nurse/therapist handover meetings. What happened in these cases is a matter for conjecture.

6.7.6 Advancing ways of determining shoulder pain

A number of equally important perspectives on assessment have been highlighted by the work presented so far. It is evident that most stroke patients use a mixture of language and behaviour to convey information about shoulder pain and that the relative weighting of each, in terms of its significance for the assessing health professional, varies according to the patient's ability to communicate. At one end of the continuum, there are patients, such as those who participated in the focus groups, who are able to describe their problems in great detail. At the other end, there are some with such severe deficits that they cannot communicate meaningfully at all. In between, there are a number who can convey some information about pain but need help to do so.

In the same way that integrating findings from qualitative and quantitative studies can lead to a more comprehensive understanding of health behaviour, so combining behavioural and self-reported information about pain can inform a more extensive understanding of someone's pain. Indeed, this is recommended by a number of researchers (Gramling & Elliott, 1992; Richards et al., 1982). Thus to enhance assessment for patients with communication deficits, this programme of research could have followed one of two alternative paths; to extend the development a scale of pain behaviour or to develop a more accessible method for self-report. It was recognised that the continued development of a behavioural assessment for post-stroke shoulder pain, will require a further series of studies comprising larger numbers of participants across to a proxy estimate by another person and this begs the question: Might there be better ways of assisting stroke patients to convey useful information about shoulder pain than are currently available? The next study describes the development of a scale of pain intensity designed for this very purpose.

Chapter 7

Development of a pictorial scale of pain intensity for stroke

7.1 Chapter overview

This chapter is divided into two interrelated parts. The first part covers the development of a scale of pain intensity with strong visual impact designed to assist stroke patients to self-report on their shoulder pain. The design of the scale (phase 1) is described first. Then follows an account of the planning (phase 2) and implementation (phase 3) of a preliminary evaluation of the scale using a quantitative methodology. This correlation study compared the new scale against two 'gold standard' pain intensity scales and determined its test-retest reliability in a group of people with chronic pain but without cerebrovascular disease. To determine acceptability of the new scale, participants ranked scales by preference and gave further comments about them, which were thematically analysed.

In the second part, a report is given of how the new scale and accompanying pictures were field tested, in collaboration with a doctor and a speech therapist, with three severely aphasic stroke patients in a rehabilitation setting. The findings are discussed.

7.2 Introduction

Although pain is a multi-dimensional construct, its reported intensity is a primary symptom informing management decisions in the clinical situation and a key measure of outcome for evaluating the efficacy of interventions for pain. The need for enhanced ways of enabling stroke patients to self-report on this has been expressed in the literature, shown by previous work in developing an ICP for managing shoulder pain and reinforced by the findings of the last study.

Despite the inevitability of some having impairments too severe to complete any self-report scale, a number may have the potential to use a scale reliably if it is designed with their specific needs in mind. Communication with stroke patients with speech and language deficits must be enhanced through as many routes as possible using clear expressive language, gesture, and imagery. Images and symbols that cross the language barrier to convey a message to people from different ethnic groups, or with low levels of literacy, appear in all walks of life. Traffic signs and pictorial instructions for operating domestic equipment are two examples. Ergonomic research into the relative usefulness of words and symbols in conveying information and understanding of this kind suggests that discrete pictographic symbols may be particularly effective, as long as the concepts being presented are not too complex. To enhance perception and meaning of symbols, they should have a simple shape with a solid boundary and avoid ambiguity. Pictures that describe actions must fulfil many of the functions of natural language, thus they should accentuate essential aspects of the actions shown (Osborne, 1982).

Clinical studies examining the effectiveness of text and pictures in information booklets designed for patients confirm that pictures significantly enhance the meaning of words in conveying medical information (Moll, 1986). And in the context of stroke, the assessment of self esteem has been facilitated by a pictorial assessment designed specifically for aphasic patients. This combines simple drawings conveying mood states, such as depression and anger, with a five-point scale of severity (Brumfitt & Sheeran, 1999). More recently, an interesting project has encouraged people with chronic pain to use visual imagery to supplement dialogue about pain, finding this a helpful way of putting across the complexity of their experiences (Vass, 2002).

The idea of developing a pictorial pain intensity scale was discussed with speech and language therapists, a doctor and a psychologist, all with specialist knowledge of patients with complex neurological conditions. They endorsed the view that a combination of simple symbols, pictures and words were likely to offer the most effective method of assisting stroke patients to communicate about pain. The following criteria for the new scale of pain intensity were therefore drawn up. These were to:

- Avoid the exclusive use of numbers, words or facial expressions
- Use imagery which conveys the concept of increasing pain
- Be as clearly visible as possible to patients with visual impairments
- Be easy to administer and score in the clinical situation
- Enable the patient to respond using gesture if they are unable to write or speak
- Have the best possible sensitivity in terms of the number of scaling categories

Rigorous development of any new scale entails testing it against one or more equivalent measures. According to Streiner & Norman (1995a), when considering how to do this, one of two choices will have to be made. Either other similar scales are available against which the new one can be compared or no other measure exists, in which case an alternative measure that taps in to the same construct can be used. Of these options, the first, that is to compare the scale against a gold standard to evaluate concurrent validity, is preferable because if the correlation is high, this will provide strong support for its validity. In contrast, the approach to determining construct validity is likely to be non-specific and less likely to result in a strong relationship.

In this case, though several pain intensity scales are considered to be gold standard and have been used extensively in general populations, none has been specifically validated for stroke patients, many of whom have been shown to find such scales difficult. Therefore testing the new scale in a non-stroke population with pain was a necessary starting point. If its psychometric properties were found to be poor, or if it was not acceptable to a general population, then it is unlikely to be useful to stroke patients. Thus the aims of this preliminary study were as follows:

7.3 Study Aims

Part One:

- To design a scale to convey the concept of changing pain intensity in a simple, clear, visual format and that would be easy to use for stroke patients with deficits affecting manual dexterity, language, vision and higher cognitive functioning.
- To evaluate the validity, test-retest reliability and acceptability of the new scale in a group of individuals with pain but without cerebrovascular disease.

Part Two:

- To investigate the utility of the scale, in association with pictures representing aspects of shoulder pain, in aphasic stroke patients in a rehabilitation setting.

PART ONE

7.4 Methods Phase 1: Scale design

7.4.1 Ideas influencing the design

Simple images reflecting the concept of pain were identified from advertisements of pain relieving products and from packaging of analgesics sold in pharmacies. The image of radiating concentric circles is used as a logo in several products, and shades of orange and red are commonly used. Using these ideas, a scale comprising a sequence of red circles was designed, thus avoiding numbers, words or faces. They were vertically aligned to potentially minimise difficulty for patients with visuospatial neglect (Roy et al., 1994). The colour red was chosen because is associated with soreness, has strong visual impact and moreover, has been used in other pain intensity scales (Grossi et al., 1985; McGrath et al., 1996). The bottom and top of the scale are anchored by two extremes simply phrased: 'No pain' and 'pain as bad as it could be', as is common in visual analogue scales. The bottom circle is white, indicating an absence of pain and the ascending five contain red circles increasing proportionally in size, suggesting increasing pain. The top circle is entirely red indicating the worst possible pain.

Although the sensitivity of a scale increases with its number of response categories, increasing sensitivity of pain scales has been associated with poorer completion by both controls and stroke patients (Price et al., 1999). It is suggested that the upper limit of useful levels on a rating scale is seven (Streiner & Norman, 1995b); in this case, to compromise between simplicity and sensitivity, six points were included. This provides one choice for no pain and five for pain of varying intensities, which aligns it with other commonly used scales using 0-5 and 0-10 scoring (Hicks et al., 2001; Melzack, 1975).

7.4.2 Appearance of the scale

Each circle is 20 mm in diameter and the diameters of each red circle within are 4, 8, 12, 16, and 20 mms respectively. These have been arranged so that the mid points of each circle are 30 mms apart; thus the distance between the mid points of the bottom and top circles is 150 mms. This size was chosen so that the smallest circle would be as clearly visible as possible, but also so that the scale would fit onto an A5 sheet of paper for convenience. The scale is reproduced in Figure 8 (page 172).

For ease of administration and scoring patients can use a paper copy and mark the circle that best indicates their pain intensity with a pen. Alternatively, it can be produced as a pocket sized laminated strip that patients can point to for another person to record. For clinician scoring, numbers from 0-5 are assigned to each circle. To simplify reference to the new scale, it will be called the Scale of Pain Intensity or SPIN.

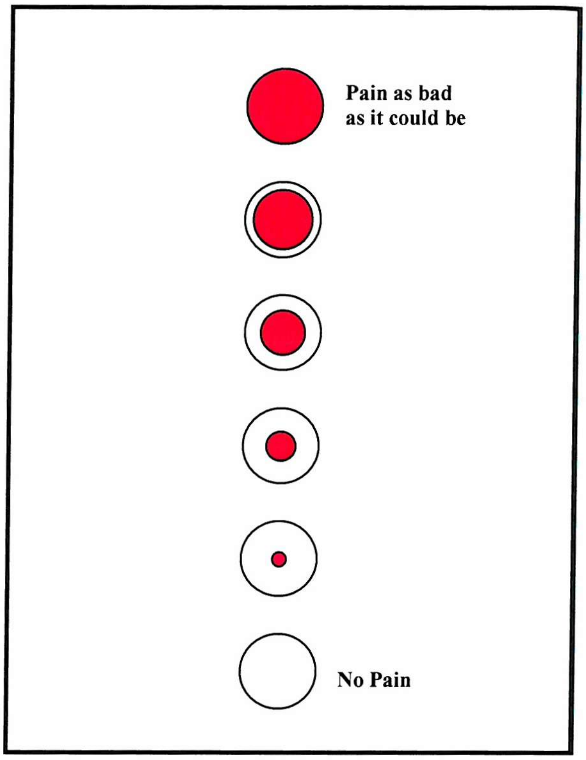


Figure 8: The scale of pain intensity (size reduced to 50%)

7.5 Methods Phase 2: Planning the preliminary study

The second aim of this part of the research was to evaluate the concurrent validity, test-retest reliability and acceptability of the SPIN in people with pain but without cerebrovascular disease. The theoretical and practical issues that influenced the study design are discussed in the following sections.

7.5.1 Choice of participants

A group of participants with painful conditions was required for the study. In-patients or out-patients could have been approached; there were advantages and disadvantages to each. Although hospital wards would have 'captive' groups of potential participants, privacy would be lacking for bed or chair bound patients. Identifying those with a primary complaint of pain, but without other discomforts that could confound pain ratings, would require careful selection and involve liaison with ward staff. They would then, for ethical reasons, have to approach each patient on the researcher's behalf, which would be time consuming for staff. Though these difficulties could be surmounted to some extent in an out-patient group, they might have been less able or willing to spare the time to participate in a research study. The main advantage of approaching out-patients, though, was that a substantial number already known to experience pain as a predominant symptom could easily be contacted by a standard letter, and willing participants could be seen in a quiet room in the hospital. This group was therefore chosen in preference to in-patients.

An introduction was established with two consultants; a rheumatologist and an anaesthetist, who both ran out-patient clinics for patients with a variety of conditions likely to cause pain. Both agreed that patients due to attend their clinics could be invited to participate. By inviting potential respondents to come ahead of their consultation, it was expected that they would be less preoccupied with other matters than afterwards. For instance, the physician might be the bearer of bad news concerning their health or, should the clinic be running late, they might be pressed for time after the appointment. The anaesthetist suggested that patients attending his injection clinic as day cases could also be included.

7.5.2 Pain experiences to be rated

A necessary consideration was to establish whether the full extent of the scale would be used by individuals rating their everyday pain experiences; that is, to investigate its usefulness in discriminating between pain of varying intensities. To achieve this, it was decided to test ratings of three painful episodes: (a) Present pain as experienced at the time of testing, (b) a specific, recent episode of severe pain and (c) a specific, recent episode of mild pain. This allowed ratings to be made of both current and remembered pain. It was decided to ask participants to describe these pain episodes in their own words and to document them for reference, so that the pain intensity scores they gave would reflect these different experiences.

7.5.3 Validity

Validity is conferred on a scale if it measures what it is intended to measure. This determines the degree of confidence that can be placed on it. Forms of validity relevant in this case were:

- Concurrent validity, tested by correlation of the new scale with one or more existing validated measures of the same construct (Streiner & Norman, 1995a).

- Construct validity further tests whether a scale measures the attribute in question and may be inferred for a pain intensity scale by comparing it with a derived composite score which represents an optimum estimation of the construct (Jensen et al., 1986).
- Face validity is the extent to which the scale is seen as acceptable, clear and relevant to its users.

To demonstrate concurrent and construct validity in this case, participants had to rate their pain intensity using the SPIN alongside one or more 'gold standard' or criterion measures for comparison. Thus the design was a correlation study, which shows how closely the measures are associated. Opinion varies as to the merits of different types of pain scale with no single one being agreed as a criterion measure. Besides individual preference, choice may depend on clinical application; that is, whether subtle or widespread changes in pain intensity need to be shown to confirm a treatment effect.

Among common well validated subjective rating scales, the 10 cm visual analogue scale (VAS) has the greatest sensitivity (Huskisson, 1983). In contrast, the 0-10 numeric rating scale (NRS) is thought to be less confusing (Bosi Ferraz et al., 1990) and to be easier to administer and score (Jensen et al., 1986). Verbal rating scales (VRSs) are also common, but although VASs and NRSs correlate fairly well, VASs do not always correlate as well with VRSs; possibly because the latter tap into an affective dimension of pain (Duncan, Bushnell, & Lavigne, 1989). For this reason, the first two scales; specifically a 10 cm vertical VAS and a 0-10 NRS were used, both to allow multiple ratings within the study and because participants' preferences were to be sought. Three scales overall, each being different in appearance, would also give more variety for comment.

7.5.4 Reliability

The test-retest reliability of an instrument is an important property that provides evidence of its accuracy and confirms its stability over time. Explicitly, when ratings are made and repeated after a time interval, comparison of the two sets of ratings should show close agreement. For the highest agreement to obtain in this case, the pain experience being rated should remain the same between tests. To show a high level of reliability; that is a minimum agreement with a correlation coefficient of 0.8 and a 95%

Confidence Interval of +/-0.1, an estimated sample size of 60 is recommended (Streiner & Norman, 1995b).

A number of factors determine the optimum timing of retest. If it is done straight away, there is a risk that people will remember their previous ratings and repeat them. Here, this possibility had to be balanced against the lability of present pain intensity, which could be influenced by a range of variables, such as recent activity levels and the timing of medication. It was anticipated that retest within a single session would increase the chance that differences in present pain scores would be due to variability in scoring rather than to a change in actual pain intensity. To minimise the likelihood of repeating remembered scores, it was decided to separate the two sets of tests by a short interview of about 15 minutes, during which standardised assessments of cognitive ability and functional limitations would be completed. Presenting the interview and assessments at this stage would serve the purpose of introducing a 'distraction' task and reduce carry over of responses between repeated tests (Bosi Ferraz et al., 1990).

7.5.5 Ethical considerations

The theoretical requirement for rigorous testing of the scale had to be balanced against the practical limitations of expecting people in pain to give their time to a study that was, on the surface, unlikely to convey them any personal benefit. It was essential to respect their goodwill and minimise any inconvenience. This was a further influence on the final decision to limit data collection to one occasion and to arrange for this to take place immediately before a pre-arranged out-patient clinic appointment.

Submissions were made to the Southampton and South West Hants Joint Local Research Ethics Committee and to the Southampton University Psychology Department Research Ethics Committee. Approval was given for the study to proceed (Appendix N), whereupon further mandatory conditions were complied with. Firstly, professional indemnity insurance cover was obtained from the University of Southampton Finance Department. Secondly, to ensure that full Crown Indemnity was in place, the study was registered with the Hospital NHS Trust Research and Development database. Thirdly, a Data Protection Guidance pack was completed and returned to the Trust Data Protection Officer. Finally an application for an honorary contract was granted to undertake a 'work placement' at the two hospitals for the duration of the study period.

7.5.6 Practical considerations

Some practical points were addressed before the study began. The procedure was discussed and tested with physiotherapy colleagues to:

- Determine the most appropriate wording to be used.
- Rehearse introducing the scales and the rating procedure.
- Check that adequate space on data sheets had been allowed for documenting data.
- Estimate the time taken to complete each section of the study.

An offer to inform doctors and nurses about the research in more detail resulted in an invitation to give a presentation about it to clinicians in one of the two participating hospitals. They approved the proposed study design. Visits were also made to each clinic to meet administrative and nursing staff, to find out about the routine in each case, to agree on the most efficient procedure for obtaining details of potential participants and to identify a quiet room with a table and chairs for testing the patients. An information sheet, which outlined the study and gave the researcher's name and contact details, was left at each clinic.

7.6 Methods Phase 3: Preliminary study

7.6.1 Inclusion and exclusion criteria

The primary inclusion criterion was that all participants should have conditions causing pain. It was to be made clear in the patient information sheet that they would be asked to rate aspects of their pain using several pain scales, so it was expected that respondents would be a self-selected group meeting this criterion. To ensure that they would understand the requirements of the study, it was decided to exclude those with cerebrovascular disease, cognitive deficits and the inability to understand English.

7.6.2 Recruitment

As participants were going to be asked to arrive an hour before their clinic appointment time, inviting consecutively booked patients was not feasible. Clinic appointment times ranged from ten minutes to an hour and predicting uptake was impossible. This meant selecting every third or fourth patient. Clinic lists were pre-screened by the researcher, assisted by clinic administrators who were familiar with the population and had access to their records. Patients were excluded if they were booked on hospital transport and if they were known to have difficulties that would preclude participation, for example the frail elderly or those with severe disabilities. Recruitment was easier from the injection clinic as patients had planned to spend the best part of the day there. In a few cases, the consultant made it known that an approach would not be appropriate, for example to patients with advanced cancer or who were in significant distress. The overall sample was one of convenience but included patients with a wide variety of painful conditions.

7.6.3 Assessments

Two assessments were included. An abbreviated form of the Hodkinson Mental Test (HMT) (Hodkinson, 1972), see Appendix O and the body care and movement subsection of the Functional Limitations Profile (FLP), reproduced with instructions in Appendix P (Patrick & Peach, 1989).

The HMT was used as a simple screening test of memory and orientation. The items included in it are similar to items in other such tests, for example, the Short Orientation-Memory-Concentration Test (Katzman et al., 1983) and the Modified Mini-Mental State Examination (MMSE) (Galasko et al., 1990). However, the HMT is easier to score than these alternatives. Although brief, it was appropriate for evaluating the normality of both short and longer-term memory in these circumstances. The original longer test has been shown to discriminate between mentally 'normal' and confused elderly people, and the shorter version correlates well with it (Hodkinson, 1972). It was reasoned that results within the normal range (≥ 7) would support the credibility of participants' remembered episodes of mild and severe pain. Any patients scoring below this range would have been excluded from analysis.

The FLP was used to determine relevant background information about participants' functional difficulties; moreover, completion required a high level of linguistic and mental functioning. It was chosen in preference to other disease specific scales, as participants were likely to have a range of conditions causing pain and to have associated functional losses. A generic scale such as this one allows scoring on a range of domains affecting manual dexterity, ambulation and daily functional activities, such as bathing and dressing. The test can be interviewer-administered or self-administered. Participants were asked whether they would prefer to complete the questionnaire themselves, or have the statements read aloud and answer verbally. In either case, instructions given by the authors were followed (Patrick & Peach, 1989), though one modification was made. When explaining how to answer the questions (see instructions in Appendix P), the original example given concerns 'driving a car', which does not occur in the body care and movement sub-section used in this study. An alternative example which does occur in this sub-section, 'standing up with help', was substituted.

7.6.4 Procedure

A flowchart detailing the procedure is shown in Figure 9 (page 179). A letter signed by the consulting doctor (Appendix Q), an information sheet (Appendix R) and reply slip (Appendix S) with pre-paid envelope were posted to prospective participants at least ten days before their clinic appointment. Those returning the reply slip who agreed to participate were sent a second letter confirming the arrangements and appointment time. Patients attending the injection clinic received modified versions of the letter and information sheet. They gave their decision about whether or not to participate at the clinic.

On arrival, participants were briefed and gave written consent (Appendix T). To ensure confidentiality, each was allocated a personal reference number under which all information was documented. All data sheets were marked with this number, with the exception of signed consent forms which were separated from the rest of the data sheets at the end of each session and stored separately. A master sheet with names and addresses of potential and actual participants, together with their personal reference numbers, was kept in a different folder. All documentation was kept locked away.

Participants were asked to describe the site of their pain and what it felt like in three situations: Pain felt at the time (present pain), a recent episode of severe pain and a recent episode of mild pain. It was emphasised that the key aspect of pain to be described was the physical feeling or sensation of pain as opposed to other aspects, such as its effect on their emotions (pain affect) or how long the episode lasted. For each situation, the site of pain and words used to describe it were documented verbatim by the researcher to form a 'pain record'. This was read back to the participant to check its accuracy. The purpose of keeping a pain record was twofold. Firstly, participants were explicitly asked to rate the intensity of their sensory experiences. Making a written record of the episodes of pain that they would be rating enabled their understanding of the task to be verified and explained further if necessary. Secondly, the three scales to be rated for the three different pain episodes (a total of nine ratings) were to be presented in random order. It was surmised that having a written prompt would minimise confusion on serial ratings.

Potential participants were contacted by letter if due to attend:
- Rheumatology out-patient clinic
- Chronic Pain out-patient clinics
- Injection day-case clinic

↓

Participants arrived an hour before clinic time and were:
- Briefed about the procedure
- Given the chance to ask questions
- Asked to sign a consent form

↓

An explanation of how pain would be rated was given:
- Descriptions of present pain and specific recent episodes of mild and severe pain were documented
- The three scales were introduced and explained

↓

The first set of pain ratings were made:
- Scales were presented in random order (9 in all)
- Each scale was removed before the next was presented

↓

Completion of standardised assessments:
- Hodkinson Mental Test
- Functional Limitations Profile (Body care and movement sub-section)

↓

The second set of pain ratings were made:
- Scales were presented in different random order (9 in all)
- Each scale was removed before the next was presented

↓

Participants' opinions on the scales were sought:
- Each scale was ranked in order of preference
- Each scale was scored from 1-5 according to ease of use
- Free comments were recorded

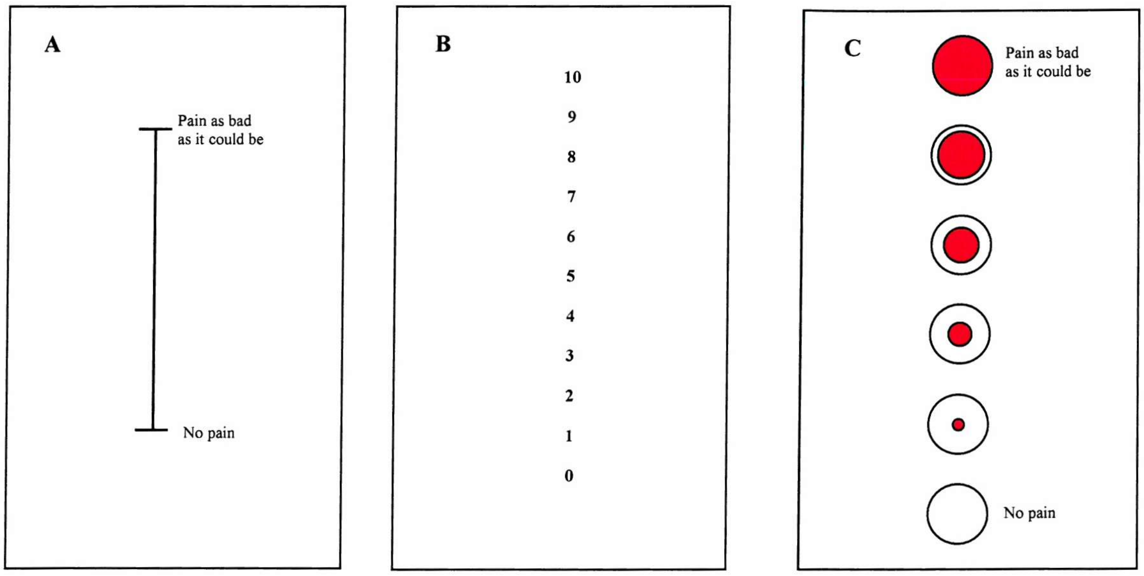
↓

Participants were thanked for their help

Figure 9: Flowchart showing the procedure followed for each participant

The three scales on separate laminated A5 sheets (Figure 10 below) were introduced and removed one at a time in a random sequence using wording as follows:[12]

> "This is [one of/ another of] the scales I will ask you to use to record your pain intensity. As you can see there are two extremes to the scale. The bottom [line/ zero point/ white circle] is for recording no pain and the top [line/ number 10/ red circle] is for recording pain that is as bad as it could be. You have a choice of where to mark your pain in between these extremes. [On scale A you will be asked to draw a line across the vertical line at the point which best represents the intensity of your pain/ on scale B you will be asked to choose and mark the number between 0 and 10 which best represents the intensity of your pain/ on scale C you will be asked to choose and mark the red circle which best represents the intensity of your pain]."



10 cm visual analogue scale | 11-point numeric rating scale | 6-point scale of pain intensity

Figure 10: The three rating scales used in the study (size reduced to 40%)

Once acquainted with the scales, each participant's pain record was placed close at hand for reference and they were asked to rate their pain intensity in each of the three episodes on each scale. To avoid bias from order effects, the scales were presented separately in a different computer generated random order for each participant, and each scale was removed before the next was presented. The following wording was used

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[12] Alternative wording as applicable to each scale in turn is given in square brackets.

before the first rating was made.[13] For subsequent ratings the opening two sentences were omitted.

> "Please remember that all the scales are for rating the intensity or strength of your pain as opposed to other aspects of it, such as how if affects you emotionally, or how long the painful episode lasted. Here is the first scale. Now will you rate the intensity of [your pain now/ the episode of severe pain you described / the episode of mild pain you described] using this scale."

Once the first set of ratings had been made, the two standardised assessments were completed and the opportunity was taken for some general conversation to add to the 'distraction element' of the pause between the two sets of ratings. After a break of about fifteen minutes, each participant's pain record was again placed close at hand as a reminder for the pain situations being rated. The nine scales were presented separately in new random order, according to the method described for the first set of ratings.

7.6.5 Preferences and views

The three laminated scales were placed in front of each participant together with a sheet for recording their responses. They were asked to number the scales in order of preference as 1st 2nd and 3rd choice; then to score each one on a five-point scale according to how easy it had been to make a decision about where to mark it. The choices given were: 1. Very easy, 2. Quite easy, 3. Not easy, 4. Difficult, 5. Very difficult. It was stressed that the same score could be given for more than one scale.

Finally, participants were invited to give free comments on each scale and reasons for their preferences. Some wrote their responses down straight away. Others found this difficult, so notes were made on their behalf if they preferred to express their views aloud. Every effort was made to be neutral when responding to their spoken comments and to avoid suggesting words where they had trouble phrasing their responses.

On completion, participants were thanked and offered a financial contribution towards the expense of spending time on the study, for example, their car parking costs. Some asked questions which led to further discussion of issues surrounding pain and its measurement. In these instances, field notes were made after their departure.

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[13] Alternative wording as applicable to each pain episode in turn is given in square brackets.

7.7 Data analysis

Quantitative methods were used to analyse demographic data and scale properties. Numerically codable data were entered into SPSS (SPSS, 2000) namely:

- Age, gender, diagnostic group, time since onset of pain.
- HMT and FLP (body care and movement) scores.
- Pain scores:
  a) VAS ratings scored as the distance in millimetres between the bottom horizontal anchor line and the mark across the scale made by each participant.
  b) NRS ratings entered as the number chosen.
  c) SPIN ratings scored from 0 (the bottom white circle) to 5 (the top red circle).
- Preference ratings were coded from 1 to 3 and ease of marking ratings from 1 to 5.

Descriptive statistics were computed and data were examined for distribution and extreme values. Apparent anomalies were investigated.

7.7.1 Scale properties

Concurrent validity was analysed by comparing the SPIN with the VAS and NRS using Spearman's correlation coefficients. Principal factor analysis was used to evaluate construct validity. Test-retest reliability of the SPIN was evaluated by percentage agreement and weighted kappa statistics and of the VAS and NRS using intraclass correlation coefficients. Because weighted kappa could not be calculated using SPSS, an alternative computer package, Stata (StataCorp, 2001), was used.

7.7.2 Free comments

Thematic analysis was used to examine free comments. They were collated and read by the researcher several times. Analysis was carried out in two stages. The first involved coding comments into 'positive', 'negative' and 'other' categories for each of the three scales (nine in all) and a tenth category of 'no comments' was included for completeness. A health psychologist and a physiotherapist researcher, who independently re-coded all the comments according to the pre-defined categories, evaluated the reliability of this classification. On completion, the two raters' codings were compared and scored by the researcher as follows:

- 1 was scored if both raters agreed on a coding category
- 0 was scored if raters disagreed on a coding category
- 0 was scored where one rater coded additional categories not coded by the other.

Percentage agreement was calculated by dividing the times both coders agreed by the number of possible instances of coding and multiplying by 100 (Boyatzis, 1998). Disagreements were resolved by consensus. In the second stage, comments agreed to be 'positive', 'negative' or 'other' were grouped under scale types. They were then sub-divided within groups according to emergent themes. A coding framework was constructed in which themes were defined, described and illustrated by examples. Its reliability was evaluated by two different pairs of raters; both psychologists, who re-coded comments according to the defined sub-themes using the method described above. Again, percentage agreement was calculated and disagreements resolved.

7.8 Results

Results are presented in the following sequence:

1. Participant recruitment and characteristics.
2. Analysis of scale properties.
3. Analysis of preferences and comments.

7.8.1 Participant recruitment and characteristics

The flow diagram (Figure 11, page 184) details recruitment. Eighty out of 203 (39%) people approached agreed to take part. They comprised 53/170 (31.2%) chronic pain and rheumatology out-patients (the proportion in each clinic group was similar) and 27/33 injection clinic day patients (82%). Among the 29 who replied but declined, nine gave an explanation. Six were unable to come an hour before their clinic appointment; two for medical reasons, one because of work pressure and three because of difficulties with transport. Two others had their clinic appointment postponed and in one case, a reply was received from a relative explaining that the patient had recently died. Eight of the 53 out-patients who agreed to take part were not after all recruited. In seven cases, postal delay meant their reply slip did not arrive until after their clinic appointment. Letters were written to those who had arrived early to offer an apology and an explanation for the absence of the researcher. The eighth did not arrive for her appointment. The final number comprised 45 out-patients and 27 day patients, 72 in all.

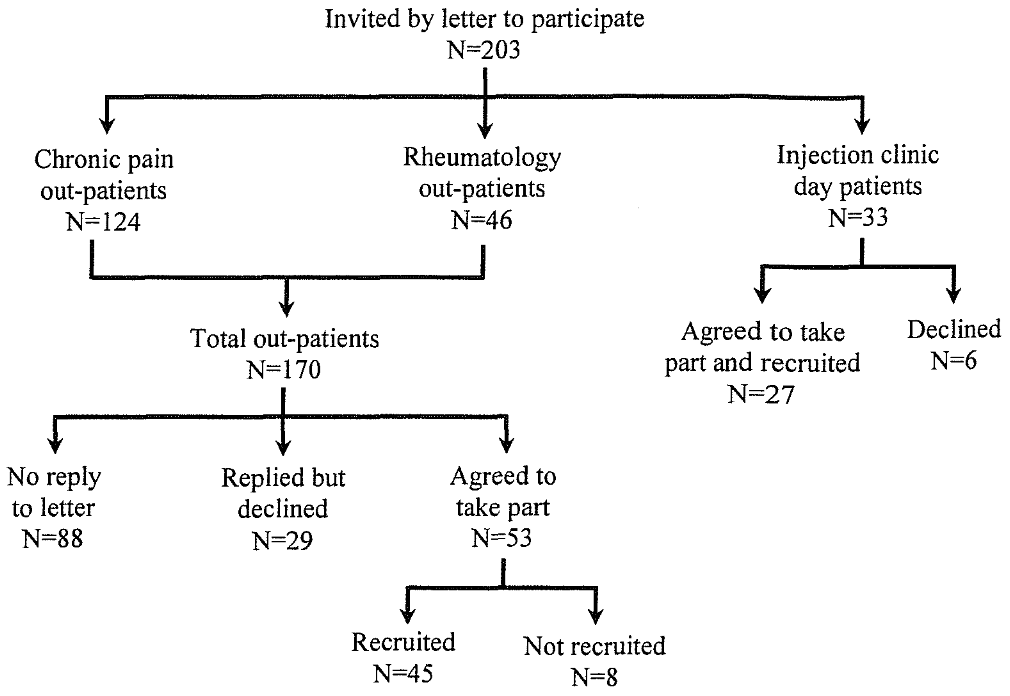

Figure 11: Breakdown of recruitment.

Participants were aged from 23 to 87 years; mean (sd) 55.6 (15.6). They were predominantly a chronic pain group who had suffered from a variety of painful conditions for two months to 35 years. Table 15 below details their characteristics.

Table 15:

Characteristics of recruited participants (N=72)

Category variables	**N**	**(%)**
Gender		
Male	32	(44.4)
Female	40	(55.6)
Diagnostic group		
Arthritis	15	(20.8)
Musculoskeletal	6	(8.3)
Low Back Pain	29	(40.3)
Neurological	6	(8.3)
Iatrogenic	15	(20.4)
Vascular	1	(1.4)
Time since onset of condition		
< 1 year	12	(16.7)
1 – 5 years	27	(37.5)
> 5 years	22	(30.5)
Unknown	11	(15.3)

7.8.2 Hodkinson Mental Test

The Hodkinson Mental Test has a maximum score of 10. Scores of 7 and above are accepted as within normal limits; all participants fell within this range. Forty-one (57%) attained the full score of 10; 23 (32%) scored 9 and 8 (11%) scored 8. Most errors were in remembering the precise dates of the First World War and in accurate recall of the whole address to be repeated at the end of the test. It was inferred from these results that none of the sample had cognitive impairments that could interfere with the ability to complete the requirements of the study.

7.8.3 Functional Limitations Profile

All participants completed the body care and movement category of the FLP, which revealed that disability scores ranged from 0 – 48%. Table 16 presents numbers of participants in bands of 10%. This distribution was positively skewed, showing that only a few participants were moderately disabled and none severely so.

Table 16:
Distribution of disability scores (N=72)

Disability score	0 – 9%	10 – 19%	20 – 29%	30 – 39%	40 – 49%
Numbers of participants	30	20	12	8	2

7.8.4 Analysis of scale properties

Descriptions of participants' pain episodes were documented on a pain record to enable their understanding of the task to be verified and to minimise confusion on serial ratings. A completed pain record is reproduced in Table 17 (page 186) to illustrate the sorts of experiences being rated.

Table 17:

An example of a completed pain record

Present pain	
Site	Lower back, worse on left side, radiating to left leg.
Description	It's a dull ache.
Severe pain	
Site	Right in the spine
Description	Last night during sleep I woke up on rolling to the side. It felt like the most awful toothache as if something was out of place, grinding and nipping.
Mild pain	
Site	Lower back
Description	After a hot bath it feels better. I never quite get rid of the dull ache but it is more bearable.

7.8.5 Distribution of pain scores

The distribution of pain scores across the three episodes of pain rated using the SPIN is shown in Table 18. Overall, ratings were distributed across the whole scale. Present pain scores spanned the full extent of the scale, with the majority occurring at points 2 and 3. Severe pain ratings clustered at the upper end and mild pain ratings at the lower end, suggesting a capacity for broad discrimination between different intensities of pain.

Table 18:

Distribution of first set of SPIN ratings for all three episodes of pain

SPIN levels	**0**	**1**	**2**	**3**	**4**	**5**
Present pain	2	10	23	23	7	3
Severe pain			1	6	30	33
Mild pain	2	31	25	9		
Total ratings	**4**	**41**	**49**	**38**	**37**	**36**

Some participants wished to rate their pain intensity between two of the numbers on the NRS (N=3), two circles on the SPIN (N=3) or between points on both NRS and SPIN (N=4). The number of intermediate scores made on the SPIN was 18 (4% of the total number of ratings made) and these were fairly evenly distributed along the scale. Four pairs were repeated between first and second ratings. Although this indicated that some participants found the SPIN (and the NRS) insufficiently sensitive, they were few in number. As this was predominantly a chronic pain group, some may have acquired an enhanced sensitivity towards their painful experiences. Without testing in other groups generalisation from these findings cannot be made.

7.8.6 Validity

7.8.6.1 Concurrent validity

Spearman's rank correlation coefficients comparing the three scales were computed for first and second sets of pain ratings. As results were similar for both sets, they are presented for the first only. All correlations were strong and significant to $p<0.001$, indicating substantial shared variance among the scales. Plots displaying interrelationships between pain ratings using the three scales are shown in Figures 12, 13 and 14 on page 188.

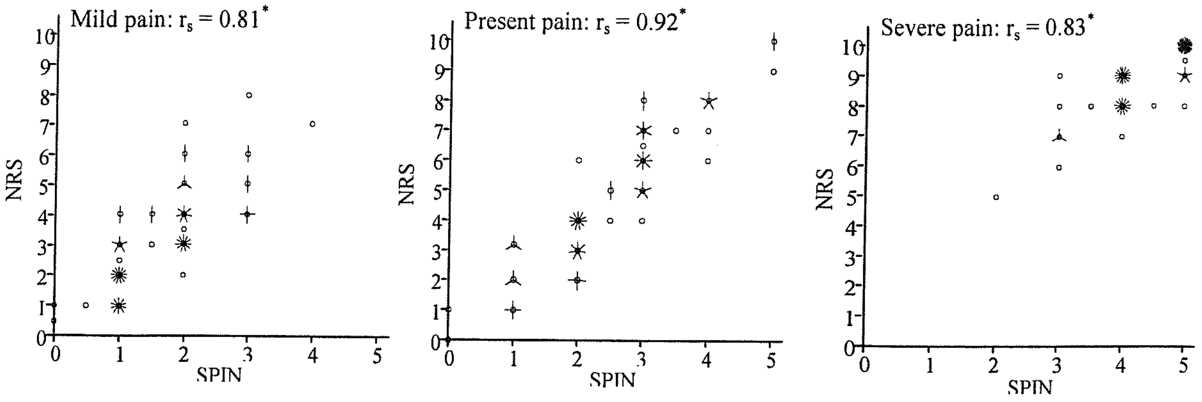

Figure 12: Sunflower plots showing relationships between NRS and SPIN ratings of mild, present and severe pain (N=72). Each petal represents one case.

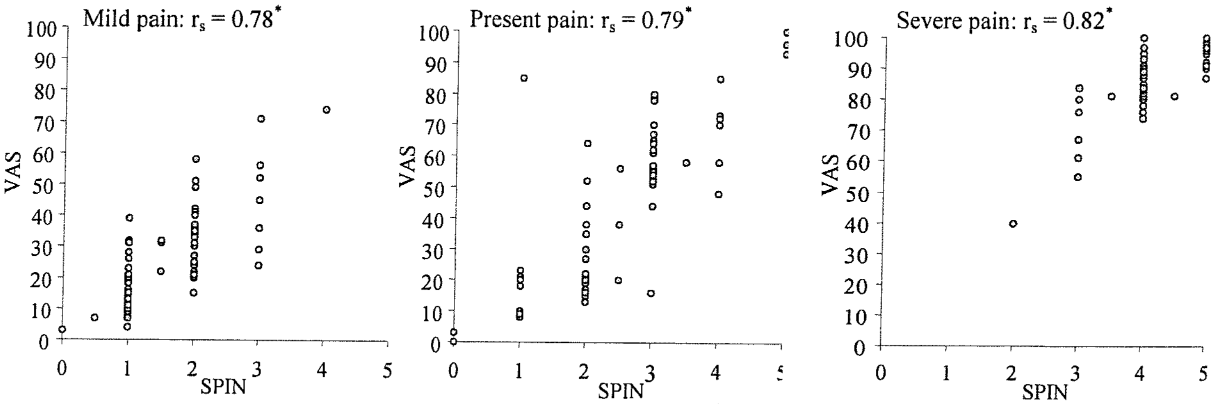

Figure 13: Scatterplots showing relationships between VAS and SPIN ratings of mild, present and severe pain (N=72).

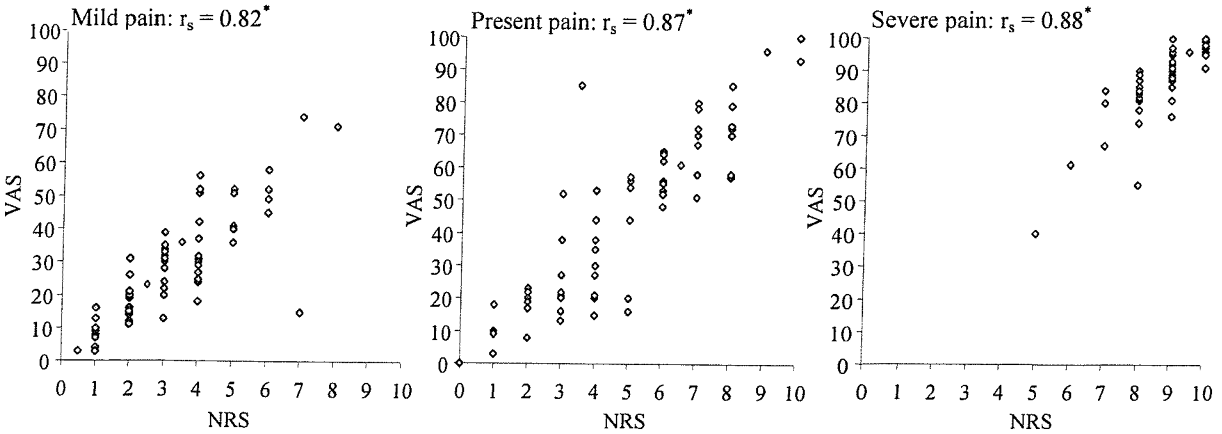

Figure 14: Scatterplots showing relationships between VAS and NRS ratings of mild, present and severe pain (N=72).

* Spearman's rank correlation coefficients (r_s) significant at $p<0.001$

7.8.6.2 Construct validity

To evaluate construct validity of the SPIN, results were compared with a 'best possible' composite measure of pain intensity using principal factor analysis. These again revealed similar results for both sets of ratings, so results for the first set only are shown in Table 19. Eigenvalues are summary measures depicting the amount of variability explained by factors in the construct under investigation. In this case, the large first eigenvalues and small subsequent eigenvalues indicated that a single factor was being measured in each case. The proportions explained by the main factor common to all three scales were 86% or more for all episodes of pain rated. Factor loadings were very close and were similar in all cases, suggesting that all three scales measured the same construct. These high values present sufficient evidence to confirm the validity of the SPIN as a measure of pain intensity.

Table 19:

Principal factor analysis on the first set of ratings of the three pain episodes (N=72)

	Factor(s)	**Eigenvalue(s)**	**Proportions explained by main factor**	**Loading of each scale on the first factor**		
				VAS	**NRS**	**SPIN**
Present pain	First	2.73	91%	0.94	0.98	0.95
	Second; third	0.2; 0.07				
Severe pain	First	2.7	90%	0.95	0.95	0.95
	Second; third	0.16; 0.14				
Mild pain	First	2.59	86%	0.94	0.93	0.92
	Second; third	0.23; 0.18				
Average loading				0.94	0.95	0.94

7.8.7 ***Test-retest reliability***

Figure 15 (page 190) shows the distribution of scores between the two sets of ratings for all three pain episodes using the SPIN.

Present pain

Second SPIN rating						
5					1	2
4				2	5	
3		2	2	17	2	
2		6	14	3		
1		7	2			
0	1	1				
First SPIN rating	**0**	**1**	**2**	**3**	**4**	**5**

Severe pain

Second SPIN rating						
5					2	31
4					28	2
3				6		
2			1			
1						
0						
First SPIN rating	**0**	**1**	**2**	**3**	**4**	**5**

Mild pain

Second SPIN rating						
5						
4				1		
3			3	5		
2		4	19	1		
1		30	1			
0	1	1				
First SPIN rating	**0**	**1**	**2**	**3**	**4**	**5**

Figure 15: Distribution of test-retest ratings using the SPIN, excluding pairs of ratings where one or both were made between scale points. Numbers in the graphs refer to the number of participants.

Test-retest reliability was first evaluated using percentage agreement. Results were lower for present pain (68.7%) than for severe pain (94.3%) and mild pain (83.3%). There were two possible reasons for this. Firstly, ratings for severe pain clustered around the highest four points on the scale and for mild pain around the lowest four points, whereas all six points were used for present pain ratings, which gave greater choice. Secondly, a number of participants, notably those with back pain, commented during testing that they were becoming more uncomfortable whilst sitting; indeed one woman was unable to sit at all and spent the time leaning over the back of a chair, stretching and pacing the room between making her ratings. This was explored further.

Of the 24 participants whose present pain scores differed on the SPIN between test and retest, reference to FLP ratings revealed that 18 (75%) had ticked the statement, *'I change position frequently'* as being true for them on the day of testing, whereas the remaining six (25%) had not. However, in the 48 whose present pain test-retest scores were the same, 31 (65%) also indicated that they changed position frequently whereas 17 (35%) did not. Although percentage values indicated a difference between these proportions, a Chi square test showed it was not statistically significant. Nevertheless, this could have accounted for the change in ratings in some cases.

Further evaluation of test-retest reliability employed weighted kappa statistics for the SPIN and intraclass correlation coefficients (ICC) for the VAS and NRS. Simple kappa coefficients give a statistic representing the chance-corrected proportion of precise agreements between two sets of ordinal data. However, this does not account for the extent of disagreement; all are treated equally. Quadratic weights base disagreement weights on the square of the amount of discrepancy giving a value identical to the ICC (Fleiss & Cohen, 1973). Thus using these weights enabled test-retest reliability of the 6-point SPIN to be compared with that of the 11-point NRS and continuous VAS. Weighted kappa statistics, together with ICC's and 95% confidence intervals are presented in Table 20 for the three pain episodes rated.

Guidelines for interpreting the strength of agreement suggest values of kappa between 0.41-0.60 to be moderate, 0.61-0.80 to be good and 0.81-1.00 to be very good (Altman, 1991). Weighted kappa statistics were all very good which suggests that the SPIN reaches an acceptable level of reliability for measuring the intensity of the sensory component of pain in the clinical situation. These results compare well with the reliability of the NRS and VAS as shown by ICC.

Table 20:

Test-retest reliability of the SPIN evaluated by weighted kappa coefficients and of the VAS and NRS by intraclass correlation coefficients (ICC), with 95% confidence intervals (CI) for present pain, severe pain and mild pain.

	Present pain		**Severe pain**		**Mild pain**	
	Wgt kappa	**95% CI**	**Wgt kappa**	**95% CI**	**Wgt kappa**	**95% CI**
SPIN*	0.83	0.59, 1.07	0.94	0.70, 1.18	0.85	0.62, 1.10
	ICC	**95% CI**	**ICC**	**95% CI**	**ICC**	**95% CI**
VAS	0.91	0.85, 0.97	0.94	0.89, 0.99	0.79	0.65, 0.92
NRS	0.88	0.76, 0.99	0.87	0.69, 1.06	0.86	0.70, 1.02

* Scores made between scale points were excluded

7.8.8 Preference and ease of use

To ascertain the acceptability of the SPIN and to identify aspects that would commend or contraindicate its further development with stroke patients, participants were asked to rate the three scales in order of preference. One had no preference. Table 21 (page 192) presents frequencies of first, second and third choices for the remaining 71.

Table 21:
Order of preference for each of the three scales (N=71)

	First choice	Second choice	Third choice
NRS	35 (49%)	27 (38%)	9 (13%)
SPIN	28 (39%)	18 (25%)	25 (35%)
VAS	8 (11%)	26 (37%)	37 (52%)

The NRS was the most popular, being the scale of choice for almost half of the participants. The SPIN was favoured by about two fifths and rated as third choice by about a third. The VAS was the least popular with just over a tenth rating it first and over half rating it as their third choice.

Participants were also asked to rate the scales according to how easy it was to decide where to score their pain using a five-point categorical scale. One could not answer this question. Table 22 presents ratings for each scale for the remaining 71. The majority of participants found all three scales very easy or quite easy. Again, the NRS was favoured over the other two scales; only a few participants found this not easy or difficult in contrast with the VAS or SPIN, both of which were found to be not easy or difficult by a fifth of the participants.

Table 22:
Ease of marking for each of the three scales (N=71)

	Very easy	Quite easy	Not easy	Difficult	Very difficult
NRS	33 (46%)	32 (45%)	5 (7%)	1 (1%)	0
SPIN	27 (38%)	30 (42%)	12 (17%)	2 (3%)	0
VAS	19 (27%)	38 (54%)	12 (17%)	2 (3%)	0

Although they had been asked to order the scales for both preference and ease of use, these ‘forced choice’ ratings did not elucidate reasons for their choice, so the free comments made were analysed further.

7.8.9 Free comments

The number of participants choosing to make no comments about the SPIN was 11 (15%) about the NRS was 13 (18%) and about the VAS was 21 (29%). It is unclear whether this was because they found it difficult to put their views into words or whether they did not have a view one way or the other. As described on page 182, comments about each scale were first coded into 'positive', 'negative' and 'other' categories before being grouped together under scale types for further coding. They were found to cluster around several themes. Within the 'positive' and 'negative' categories, two themes emerged: (a) the choice of rating afforded by each scale and (b) how the scale related to the pain experience. Within the 'other' categories, two different themes emerged: (a) a neutral view, suggesting neither a preference nor an aversion to the scale and (b) ambiguity or uncertainty about use of the scale. In summary, four different sub-themes were identified. These are described, defined and illustrated in the coding framework (see Table 23, pages 194 and 195).

Table 23:

Coding categories for comments on VAS, NRS and SPIN

Label	Definition	Description	Examples
1. Positive comments about VAS	Words describing positive features of the VAS	Subjects commented favourably about using VAS as a means of scoring pain intensity. Included are: a) comments about choice on the scale for scoring pain; b) comments about relating the scale to the experience of pain	a) Wider choice b) The line seems to relate to pain on a sliding scale
2. Negative comments about VAS	Words describing negative features of the VAS	Subjects made adverse comments about using the VAS as a means of scoring pain intensity. Included are: a) comments about choosing where to score pain on the scale; b) comments about relating the scale to the experience of pain	a) More difficult to find a space on the line b) It doesn't convey anything
3. Other comments about VAS	Other descriptions of the VAS which are neither positive or negative	Other comments include: a) neutral comments which suggest neither a preference nor an aversion to the scale; b) ambiguous comments which suggest uncertainty about use of the scale	a) Could mark arrows up or down to show level of pain after time lapse b) Just as easy, but harder to judge
4. Positive comments about NRS	Words describing positive features of the NRS	Subjects commented favourably about using NRS as a means of scoring pain intensity. Included are: a) comments about choice on the scale for scoring pain; b) comments about relating the scale to the experience of pain	a) More sections for choice b) Can think of pain in terms of numbers
5. Negative comments about NRS	Words describing negative features of the NRS	Subjects made adverse comments about using the NRS as a means of scoring pain intensity. Included are: a) comments about choosing where to score pain on the scale; b) comments about relating the scale to the experience of pain	a) If I'm in pain I can't decide what number to choose b) Numbers are just ordinary, don't relate to pain

Table 23: (continued)

Label	Definition	Description	Examples
6. Other comments about NRS	Other descriptions of the NRS which are neither positive or negative	Other comments include: a) neutral comments which suggest neither a preference nor an aversion to the scale; b) ambiguous comments which suggest uncertainty about use of the scale	a) It takes a little longer to make a decision on scale of pain when looking at numbers b) Slightly frustrating though an obvious way of scaling
7. Positive comments about SPIN	Words describing positive features of the SPIN	Subjects commented favourably about using the SPIN as a means of scoring pain intensity. Included are: a) comments about choice on the scale for scoring pain; b) comments about relating the scale to the experience of pain	a) Good range to define pain b) Colour helps to show how the pain feels
8. Negative comments about SPIN	Words describing negative features of the SPIN	Subjects made adverse comments about using the SPIN as a means of scoring pain intensity. Included are: a) comments about choosing where to score pain on the scale; b) comments about relating the scale to the experience of pain	a) Choice is not so good b) The circles do not seem to relate to the pain
9. Other comments about SPIN	Other descriptions of the SPIN which are neither positive or negative	Other comments include: a) neutral comments which suggest neither a preference nor an aversion to the scale; b) ambiguous comments which suggest uncertainty about use of the scale	a) Difficult because pain variable from moment to moment b) Circles could be confusing but I don't know why
10. No comments	No text entered in table	Any sections of the table without comments	. . .

After excluding cases where no comments were made, inter-rater reliability was evaluated initially by calculating percentage agreement between the two raters who had coded comments into 'positive', 'negative' and 'other' comments. Agreement exceeded 75% in all cases, so reached a good level of reliability. The distribution of agreements across the three scales is shown in Table 24. Coding differences were discussed until a consensus had been reached so that sub-divisions could be analysed further.

Table 24:
Inter-rater agreement of coding categories for comments

	NRS	**SPIN**	**VAS**	**Combined**
Times both coders agreed Times coding was possible	47/62	52/64	41/49	140/175
Percentage agreement	76%	81%	84%	80%

Percentage agreement of themes within each category as coded by the second two raters is shown in Table 25 and was inconsistent; agreement was especially poor in two of the 'other comments' categories, where there were small numbers. A final judgement was arrived at through comparing disagreements with initial coding made by the researcher and taking into account the preference and ease of use ratings.

Table 25:
Inter-rater agreement of themes within positive, negative and other categories

		NRS	**SPIN**	**VAS**
Positive comments	Times both coders agreed Times coding was possible	25/39	28/37	9/12
	Percentage agreement	64%	76%	75%
Negative comments	Times both coders agreed Times coding was possible	8/14	24/28	22/32
	Percentage agreement	57%	86%	69%
Other comments	Times both coders agreed Times coding was possible	5/6	1/2	3/7
	Percentage agreement	83%	50%	43%

The NRS attracted the greatest number of positive comments. Participants preferred it for several reasons. Almost a third cited previous experience and familiarity; *'I am used to using numbers daily and they are a familiar concept used by my G.P.'* Others found they could relate their experience of pain better to a numbered scale and two could, *'think of pain in terms of numbers.'* On the other hand, several found numbers conceptually more difficult, *'It's more difficult to understand the numbers of your intensity.'* Overall, having 11 choices on the scale and being able to target their experience of pain to a specific point was regarded as the best combination among the three scales.

The SPIN also attracted positive comments from over half the participants. Reasons for preferring it clustered around the theme of relating the scale to the experience of pain. The visual properties were particularly helpful to some. *'The visual image makes it easier to relate to pain. It relates to throbbing pain and describes it best.'* And from a different perspective, *'The size of shape shows quantity of pain.'; 'The red centre relates to pain being mild or all consuming.'* On the downside, two participants found it respectively, *'confusing'* and, *'harder to understand.'* Nineteen participants criticised the limited choice for scoring, though one, reflecting on her hospital experience after an accident, said she would have found the SPIN easier to see and less demanding to rate at that time, since fewer choices would have required less thought. Some said it would be confusing if there were more choices and several others volunteered that more choice would have placed the SPIN on a par with the NRS.

Lastly, the VAS only attracted positive comments from a minority of participants, though a few found the greater choice helpful. *'More flexibility – you can choose to be at any point on the pain scale'* or found it conceptually more meaningful, *'Easier to put correct representations of pain.'* However, a far greater number found it difficult to judge where to rate their pain on the line, *'not very accurate - sort of random'* and some commented that divisions would have helped, *'it was almost guesswork. In my mind I was trying to work it into numbers first.'*

In summary, the free comments supported and clarified the 'forced choice' ratings. There was a strong preference for the two ordinal scales with participants finding it easier to target their pain experience to a defined point as opposed to judging where to mark a continuous line.

7.9 Commentary on part one

The first part of this chapter described the development of a pain intensity scale designed for stroke patients. Preliminary testing in a group of patients with pain but without cerebrovascular disease or other cognitive deficits suggested that the SPIN could discriminate between different ratings of pain intensity. It compared well with two criterion scales, meeting the requirements for both concurrent and construct validity, which commends it as a measure of pain intensity in a general adult population.

Test-retest reliability of the SPIN was similar to the two other scales, though the relatively short time between test and retest could be criticised. As people may repeat a remembered score, to limit this as a potential confounding factor, it has been recommended that retesting should not usually take place within two days (Streiner & Norman, 1995b). However, if the phenomenon being rated is as labile as present pain intensity, less reliance can be placed on repeated ratings after two days because there may be a genuine reason for a change in intensity.

In their classic study, Peterson & Peterson (1959) showed that unless it had been rehearsed, retention of verbal information in short-term memory could be prevented by a distracter task, such as counting numbers backwards. When the distraction time exceeded 18 seconds, recall dropped to almost nothing. The optimum timing of a distracter task that would prevent recall of subjective pain ratings has not been experimentally determined. However, to minimise bias from recall during this study, the two tests each comprised nine different ratings in random order and these were separated by a 'distraction interview', which included administering a measure of functional limitations and a mental test in which one task involved counting backwards from 20 to one. The time taken to explain and administer these tests amounted to approximately 15 minutes. A similar method has been used by others to reduce carry over of responses between repeated measures of pain (Bosi Ferraz et al., 1990).

Even with this short time between first and second ratings, lower test-retest reliability for present pain intensity was found. This may, in part, have reflected the fluctuating nature of pain, as evidenced by participants who commented that it had become worse on sitting during the study. It is unlikely that the reliability of present pain ratings would have been any greater with increased time between retest. Nevertheless, in the continued development of the SPIN, it would be useful to repeat this study, rating different aspects of remembered pain with a longer interval between test and retest, to further evaluate the stability of the scale.

Despite the acknowledged difficulty of converting personal, subjective experiences of pain into concrete ratings using VASs and NRSs (Williams, Davies, & Chadury, 2000), few studies have explored their symbolic properties and the influence that choice of scale could have on the validity of ratings. As a visual language has been found helpful in enabling people to convey the meaning of their pain experience to others (De Souza and Frank, 2000; Vass, 2002), it is conceivable that a visual scale could assist some people to convey their pain intensity more meaningfully than some other types of scale. In support of this idea, many participants commented on aspects of the SPIN's appearance that helped to reflect their experience of pain, which endorses its face validity in a general population. Not surprisingly, the colour red was associated with pain because they knew that this was being rated beforehand. People without this knowledge might perceive the colour differently, for example as representing anger, and this should be investigated further. A number of participants related the magnitude of the red circles to the 'quantity' of their pain. Making the conceptual link between a visibly increasing area and greater pain intensity appeared to be intuitive for some, but less obvious for others. Leaving aside the VAS, which was least preferred, participants broadly divided into two groups; one finding numbers easier to use and relate to pain and another finding the visual scale more helpful on both these counts.

However, the NRS was the preferred scale and found easiest to use by the majority of participants. This finding endorses a growing consensus among pain specialists that the NRS should be the scale of choice for clinical and research purposes (Rowbotham, 2001), so the decision to design yet another scale could be questioned. It is, though, equally accepted that certain groups of people with communication deficits have special needs as regards pain assessment, that there are few well designed instruments for them to use and that this omission may have detrimental consequences (Hadjistavropoulos, von Baeyer, & Craig, 2001). Stroke patients fall squarely into this category, but as a diverse population, a choice of pain assessment instruments may be needed to capitalise on their strengths and compensate for their weaknesses. Allowing individual preference to determine which pain scale has greatest meaning, and which is easiest to use, may optimise its face validity, a view supported by others (Herr et al., 1998).

The main limitation of the SPIN was the lack of choice for scoring, which was criticised by a quarter of participants and further highlighted by the few who rated their pain between points on the scale. Some had chronic pain conditions of many years standing and may have been particularly sensitive to subtle changes in their pain intensity. However, others said that the SPIN was simpler to use precisely because there were fewer points to choose from. For a pain intensity scale to have clinical utility it must be sensitive enough to show change in relation to intervention, or over time. As a change in pain of 2 points on a 0-10 NRS has been shown to represent a clinically important difference (Farrar et al., 2001), a change of 1 point on the SPIN has the potential to match this level of sensitivity. This should be investigated in a responsiveness study. It is likely that increasing the number of points on the scale would make it more confusing for stroke patients and moreover, as it stands, it aligns with other scales scored on a 0-5 or 0-10 basis, so there are as yet no compelling reasons to change it.

7.10 Introducing the SPIN to stroke patients with language impairments

Having carried out a preliminary evaluation of the SPIN in a general population with pain, and as continued investigation was justified by the findings, judging its usefulness for stroke patients was indicated. Prior research had shown that a proportion undergoing rehabilitation 'fail' the AbilityQ screening test, denoting their inability to comprehend existing pain rating scales. But would the visual SPIN be conceptually easier for this group to understand and use, and how should it be presented and explained? First and foremost, these questions demanded methodological answers because the method used to evaluate the SPIN in a general population could not realistically be replicated in aphasic stroke patients. So to inform further development, a pilot case study, which is reported here in narrative form, was undertaken.

PART TWO

7.11 Rationale for the design

An exploratory case study provides a flexible method for shedding light on the complexity of individuals and/or social settings and may lead to the formulation of propositions for further inquiry. In medicine, case studies commonly illustrate unusual or interesting manifestations of illness; the case may be a single patient or several can be combined as multiple cases. However, a case can also mean an entity such as an institution, a social group or a social process. In these circumstances, it is important to define what the case is as a basis for delineating the data needed to explore it and to relate it to the theory of what is being studied (Yin, 1994). Here, the process of communicating information about pain intensity using the SPIN was defined as the case and in theoretical terms, this fitted the encoding to decoding component of the Model of Pain Communication (Hadjistavropoulos & Craig, 2002). Yin (1994) enumerates the benefits of conducting a pilot case study as: providing insight into the basic issues being studied, identifying useful sources of data, clarifying the logistics of data collection for future studies and as a means of trying different approaches on a trial basis. All these were pertinent to developing the SPIN.

7.12 Reflections on preliminary planning

The first task was to determine how to explain the SPIN to aphasic patients. As there was no precedent for this, I reasoned that the pragmatic solution was to try it out in a clinical setting. This was facilitated in that development of the shoulder pain ICP, with its associated rounds of audit, was still current on the RRU. As explained in section 6.4.3, page 134, this project was funded by the North West Thames Regional Health Authority, had been subject to scrutiny by the Trust's Research and Development Department and had been approved. In theory, this allowed for the design and evaluation of new assessments for shoulder pain, such as the SPIN, without formal ethical approval. However, in a situation where audit and research coincide, and where the use of audio and video-recording was planned, the decision to proceed without supplementary approval from the Local Research Ethics Committee could rightly be criticised and strictly speaking, such approval should have been obtained. Nonetheless, ethical principles were rigorously adhered to at all stages of the study; in particular using pseudonyms to maintain confidentiality and obtaining informed consent from participants.

I recognised that input from other members of the rehabilitation team during this exploratory stage would be invaluable. Not only would this be true to the spirit of the multi-disciplinary approach that had underpinned the development and evaluation of the ICP process, but it would have the specific benefit of allowing multiple perspectives to be taken into account during the process of data analysis.

The doctor co-ordinating the shoulder pain ICP was keen to participate and the assistance of Alison, a specialist neurological speech and language therapist employed on the RRU, was also enlisted. She had already been involved in administering the AbilityQ and ShoulderQ to dysphasic patients and, as someone trained to assess communication deficits in stroke patients, was experienced in facilitating interaction with them in the clinical setting. She agreed to collaborate in an initial trial of the SPIN by introducing it during routine therapy sessions.

7.13 Supplementing the SPIN with pictorial representations of pain

As proposed at the beginning of part one, a combination of symbols, pictures and words can promote understanding in stroke patients. So to supplement the SPIN, illustrations representing no pain and three aspects of shoulder pain were drawn (see Figure 16). Pain on movement, pain at rest and pain at night were chosen as the circumstances of pain about which information is needed to guide interventions such as analgesia. Jagged lines draw attention to the site of pain on each drawing. Initially these were black, but on the advice of an independent specialist speech and language therapist, red was used to reinforce the conceptual link between the drawings and the SPIN.

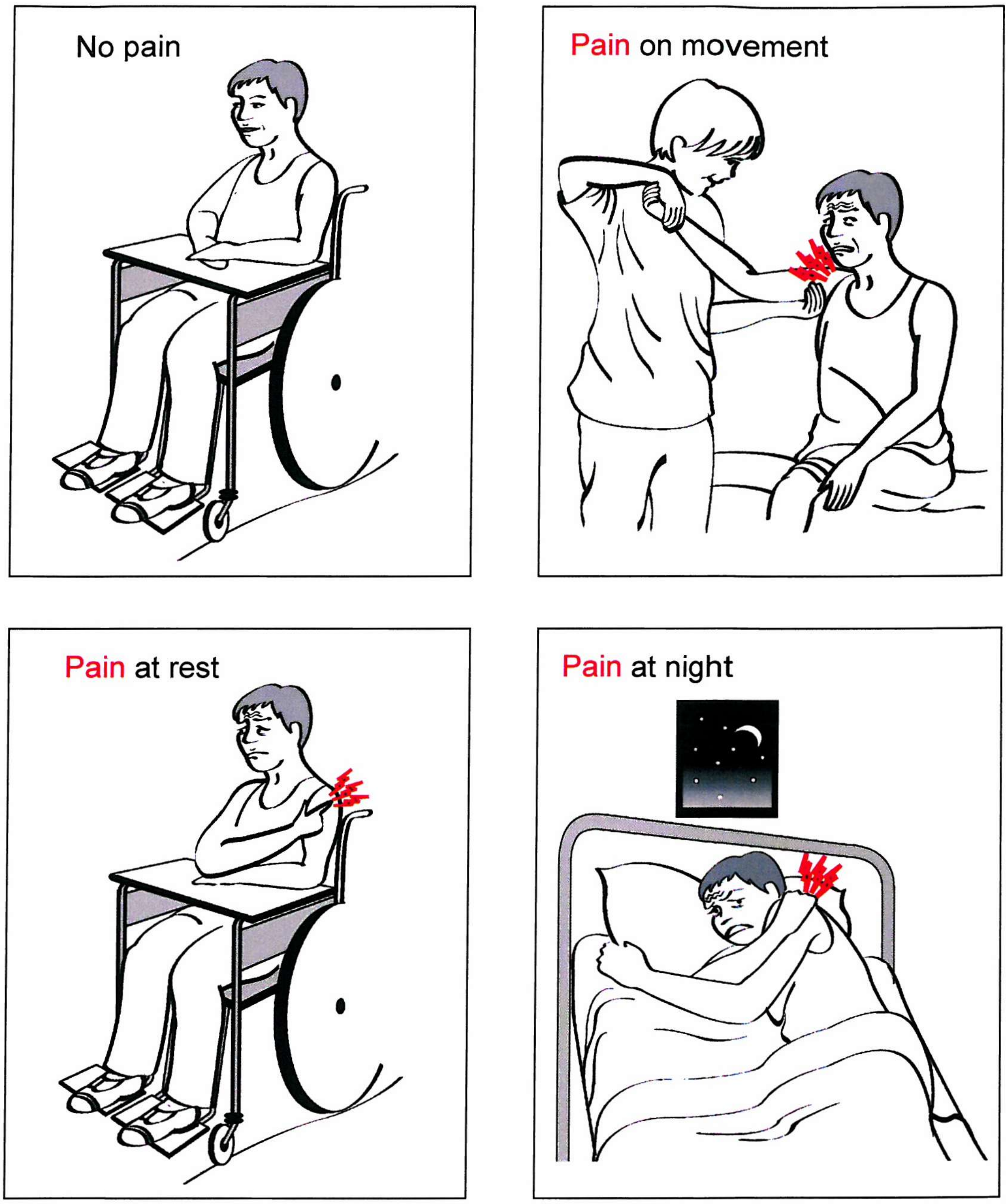

Figure 16: Drawings representing no pain and three aspects of shoulder pain

7.14 Aims

The aims were to:

1. Determine how to present the pictorial SPIN to dysphasic stroke patients
2. Explore ways of establishing conceptual understanding of it.
3. Ascertain whether it could be used to facilitate self-report on the circumstances and severity of shoulder pain.

7.15 Outline of methods

To meet the first aim, Alison introduced the SPIN to two aphasic patients with shoulder pain, in the presence of their doctor and myself, during routine speech therapy sessions. Findings from these sessions informed a series of steps that were ordered in booklet form. To meet the second aim, the booklet was used to explain the SPIN to a third aphasic patient, who subsequently made serial ratings of his shoulder pain over several weeks. The pattern of his change in pain was analysed and compared with his analgesic record and progress reports in his multi-disciplinary ICP notes. Sources of evidence for analysis comprised interviews, participant observation and ICP documentation.

7.15.1 Patient participants: Phase 1

Two patients with shoulder pain who had 'failed' the AbilityQ were identified. Both had sustained left middle cerebral artery infarcts with right-sided hemiplegia.

Joshua, aged sixty-three, was eleven weeks post stroke on admission to the RRU. He had a subluxed hypotonic shoulder, hemineglect, and hemianopia. His admission speech therapy assessment showed moderate receptive and severe expressive dysphasia and verbal dyspraxia. He was unable to understand complex verbal information but his reading improved when supported with pictures. Severe ideomotor dyspraxia meant he had difficulty using gesture, drawing, writing and pointing effectively to communicate. His yes/no response was unreliable. He was tested with the SPIN two weeks after his admission.

Ben, aged fifty-four, was admitted to the RRU fourteen weeks after stroke onset. He had a hypertonic shoulder with mild malalignment of the shoulder joint. He also had severe right-sided hemineglect with a possible hemianopia. His admission speech therapy assessment showed severe receptive and expressive dysphasia. He had reduced comprehension for both verbal and written language and significant ideational and ideomotor dyspraxia, which meant he was unable to use gesture and pointing to indicate his needs. He had good use of facial expression but his yes/no response was unreliable. By the time he was tested with the SPIN, he had been on the RRU for twelve weeks and had made some progress. He was able to point and to give a reliable yes/no response to basic questions. He could understand verbal information when facilitated with gesture and pictures.

7.15.2 Procedure: Phase 1

Alison explained to each patient that she wanted him to tell her about his shoulder pain using a new scale. She asked if the doctor and a researcher could observe the session and if it could be audiotaped. She used a combination of words, gestures and sketches on paper to convey the sense of what was proposed and showed them the tape recorder. She was satisfied that both patients understood and agreed.

To accurately reflect the way new concepts are introduced to patients with communication deficits in a clinical setting, and because patients' speech and language deficits are rarely identical, Alison was given freedom to conduct each session according to her professional judgement. She had laminated copies of the four pictures, together with the SPIN, to introduce as she thought best. She also used pencil and paper to write simple words and signs to reinforce the meaning of what she was conveying. The sessions of both patients were transcribed verbatim.

7.15.3 Interpretation of sessions

On discussing our impressions, we concluded that though Joshua found the pictures meaningful, his use of the SPIN was inconclusive. This was because he indicated by saying 'no' that he no longer had shoulder pain at rest or at night. To reinforce the idea of pain on movement, the doctor lifted his arm and he indicated that it was slightly painful by his facial expression and by his verbal response. With encouragement, he pointed to point 1 on the SPIN. We were unable to determine more from this session.

Ben's understanding of the SPIN was also uncertain. He was equivocal about indicating yes/no when asked if he had pain at rest or on night and made no attempt to point at the SPIN. He indicated that his arm hurt on movement and gestured around points two and three of the SPIN, but would not commit himself to a specific point. During the subsequent discussion Alison pointed out that comprehension for him was very context specific, so that he would only able to indicate something he was actually experiencing at the time. Therefore rating something remembered, such as pain at night, would be beyond his ability. A further problem may have been his severe visual field deficit. She had watched him scanning the SPIN carefully but wasn't sure how well he could see the full extent of the scale. She gained the impression that he did understand the pictures because from her experience, he would always let her know if he didn't understand something.

The transcripts were read several times and the techniques Alison had used to explain the SPIN were noted and discussed. A simple set of steps were identified that formed the basis for teaching use of the SPIN and for determining some aspects of patients' understanding of the task. The content and order of the explanation and questions was refined to include the simplest words and to specify when gesture could usefully supplement meaning. The following steps were identified and a script was written to standardise its presentation.

7.15.4 Steps to evaluate understanding

1. To determine the ability to reliably indicate 'yes' and 'no', these two words in large print were supplemented respectively with a large tick and a cross for clarification. The patient was to be asked the following questions:
   a) 'Please show me yes.'
   b) 'Please show me no.'
2. To see if the patient could distinguish between no pain and shoulder pain, the pictures showing 'no pain' and 'pain at rest' were to be shown and, using a facial expression indicating pain as appropriate, the following questions asked:
   a) 'Which picture shows shoulder pain?'
   b) 'Which picture shown no pain?'
3. To test for a visuospatial deficit which could confound use of the scale, the patient was to be shown the SPIN and, along with appropriate gestures, was to be instructed as follows:
   'Here are some circles. Can you point to each one?'
4. To explain the purpose of the scale, the following wording was to be used and accompanied by appropriate gestures:

'This is a pain scale. The white circle means no pain. The red circles mean pain. As the red circles get bigger, the pain gets worse. The top red circle shows pain as bad as it could be.'

5. To determine the patient's ability to indicate shoulder pain on him/herself, the following questions were to be asked and assisted by the 'yes' and 'no' responses:
    a) *'Do you have pain in this shoulder?'* (Indicate the affected arm).
    b) *'Can you show me where?'*
6. With the picture indicating 'pain on movement', and assisted by the 'yes' and 'no' responses, the presence or absence of pain was to be established by asking:
    'Do you have pain in this shoulder when your arm is moved?'
7. To test the patient's ability to indicate pain severity using the SPIN, the following question was to be asked and accompanied by gesture as appropriate:
    'How bad is the pain when your arm is moved?
8. Steps 6 and 7 were to be repeated for pain at rest and pain at night.

Having developed a structured format to teach use of the SPIN and to assist in determining patients' conceptual understanding of the task, the second aim was to ascertain its use to facilitate self-report of the circumstances and severity of shoulder pain in another dysphasic patient. A booklet incorporating each step on a new page was produced. So that a record of its presentation, together with the use of accompanying gestures and any observed pain behaviours could be kept for future analysis, it was decided to seek consent to videotape the planned session.

7.15.5 Patient participant: Phase 2

A third patient was identified from ICP documentation as unable to self-report on his pain and confirmed by members of the team as being appropriate for the next phase of the study. Graham, aged forty-three, had sustained a large left middle cerebral artery infarct. He was admitted to the RRU ten weeks after stroke onset. His initial speech therapy report stated that he had significant language impairments including receptive and expressive dysphasia and verbal dyspraxia. He had limited use of hand gestures but was able to indicate 'yes' and 'no' and found pictures easier to understand than words. He had right-sided hemiparesis with severe upper limb impairment. His right shoulder was hypotonic with inferior/medial shoulder subluxation. He had minimal active arm movement and intense upper limb pain during passive movement, which limited participation in therapy. It was inferred that pain was localised to his shoulder, but that there was also a neuropathic component. His physiotherapy report stated: *'He indicated severe pain in his right arm. It was difficult to obtain an accurate pain behaviour pattern due to his dysphasia.'*

7.15.6 Procedure: Phase 2

As he was having difficulty communicating about his shoulder pain, and because it was clearly causing him some distress, Graham was asked by Alison, in the presence of his wife, if he would consider trying out a new pain scale. Because it was important to know how easy it would be for clinicians other than speech and language therapists to administer the SPIN, I conducted this part of the study. Graham and his wife were asked if they would be willing to meet a researcher who would explain what was entailed in more detail. They agreed, and the plan was discussed. Graham's wife remained involved throughout. A pictorial information sheet was designed and used to assist Graham's understanding of the proposed videotaping procedure (Appendix U). His informed consent using a pictorial consent form (Appendix V) was obtained; this was witnessed and countersigned by his wife.

I went through the sequence of steps outlined in section 7.15.4 and explained each step using simple language and gesture. Graham seemed to understand what was required and pointed to circles on the SPIN to rate his pain at rest, on movement and at night. Afterwards, the doctor who was videotaping the session, Graham's wife and I shared impressions of his ability to understand the task and judged that his ratings did seem to reflect his pain intensity, which was perceived by the team to be severe. However, it was still not possible to tell for certain whether he had full conceptual understanding of the task.

To explore this further, a report-report comparison; that is between patient self-report and reports from other significant individuals (Schlund, 1999) was planned. It was agreed to conduct a second baseline session with Graham to reinforce use of the SPIN before commencing daily self-report pain ratings to monitor his pain over time. These were to be collected and kept separately from the ICP records to avoid biasing proxy reports from members of the team. By retrospectively comparing these ratings with his analgesic record and with entries in the case notes, any concurrence between the two would support the credibility of his ability to self-report on pain using the SPIN.

7.15.7 Problems with continuity of the study

Unfortunately, just after the first baseline session, Graham had a seizure. His prescribed medication made him drowsy, so he was unable to continue until this problem had been resolved. Once able, he completed a second baseline session that was also videotaped. Because the first session was perceived to have been successful, some additional questions that matched those included on the AbilityQ were included in the second session. These asked if Graham could point to the largest, smallest and middle sized red circle and were designed to test whether he could comprehend the concept of a change in size presented visually. He found this extremely confusing. Later discussion with Alison and his wife revealed their view that recognising the meaning of the abstract terms *'large'*, *'small'*, *'red'* and *'white'* was beyond his linguistic ability.

Daily ratings of pain on movement, at rest and at night were subsequently initiated. It had became apparent that there was no need to go through the whole sequence of steps each time, so a laminated set of pictures representing each of the three circumstances of pain were presented one by one alongside the SPIN to prompt ratings as appropriate.

7.16 Results

The results of serial ratings made weekly in blocks of five days are shown in Figure 17 on page 210. One set of ratings was missed during week two and is shown by dotted lines.

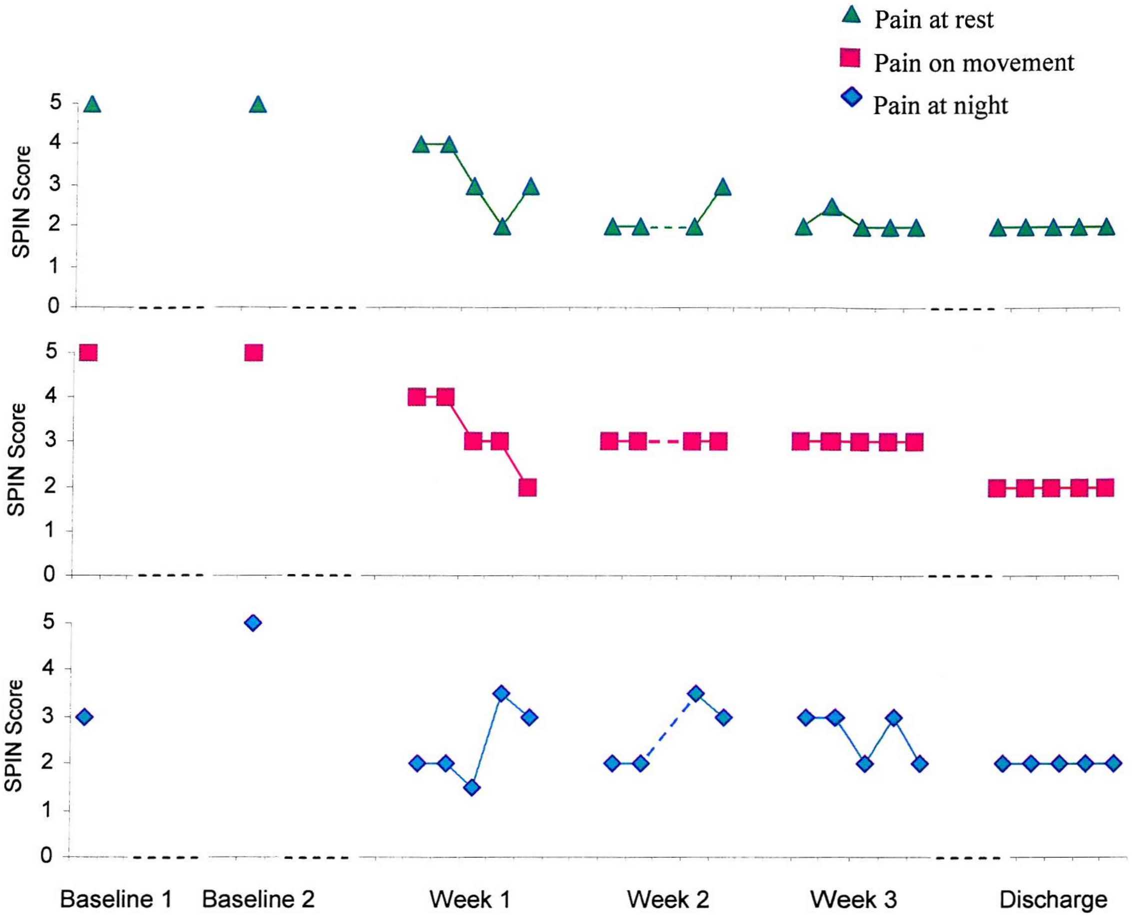

Figure 17: Graphs showing change in SPIN scores

7.16.1 Serial pain scores

At the time Graham made his initial baseline ratings he was taking Tramadol and Paracetamol for pain. Despite this, he indicated five on the SPIN for pain at rest and on movement. He indicated three for night pain. After his seizure he was prescribed Carbamazepine which has an analgesic effect. However, because he became drowsy and was unable to participate in therapy, this was withdrawn. Once he had recovered, the second baseline set of ratings was collected. He indicated five for each pain situation and proxy reports in his case notes confirmed that his pain was severe and uncontrolled by medication. Carbamazepine was recommenced at a lower dose and, as his general condition had stabilised, he began regular daily pain ratings using the SPIN.

Graham's SPIN scores fluctuated daily. He differentiated between intensity levels for the three kinds of pain, which indicated he was not perseverating. Indeed, he indicated some scores in between scale points, which suggested sensitivity to subtle changes in pain. By week three, his self-reported pain at rest and on movement had settled at around three and he had progressed to independent washing and dressing. His therapy report stated: *'Pain still exists; complaints during functional tasks reduced.'* By discharge, he was consistently scoring two and his therapy report stated: *'Pain continued to be present but significantly improved.'* He was spontaneously using his right arm to carry objects while walking and despite pain, he was willing to use his right arm as much as possible.

In summary, Graham's self-reported pain ratings showed daily fluctuations but overall, pain reduced from five to two at rest; five to three on movement and three to two at night. This pattern of change over time reflected changes in his medication and was consistent with independent reports documented in the case notes by members of the rehabilitation team.

7.17 Discussion

Stake (1998) maintains that *'A case study is both the process of learning about the case and the product of our learning.'* This was demonstrated here. The iterative process of discovery, which came from the analysis of interactive sessions with two different patients, was essential to the development of a coherent method of presenting the SPIN. In turn, new insights were discovered during the second stage of testing that will further inform its use. This project combined the skills of several different members of a rehabilitation team and demonstrated how research of this nature can gain from collaboration that crosses professional boundaries. For all these reasons, the method proved its value as a way of exploring the complex process of communicating about shoulder pain with patients for whom the only alternative was proxy report.

Drawing conclusions about the efficacy of the SPIN from the results presented here can only be tentative, but do support its further evaluation in the population for whom it was designed. Since Joshua's shoulder pain had virtually resolved by the time of testing, we did not pursue the SPIN further with him. In Ben's case, though we thought that he recognised the pictures as showing pain, we judged his conceptual understanding of the SPIN to be poor. As shoulder pain was not a significant problem for him, there seemed little point in continuing with further sessions to teach its use at the expense of his more important planned speech therapy programme. On the other hand, there was agreement among members of the team involved that once 'the penny dropped', Graham could use the SPIN effectively to self-report on his pain. This suggests a learning effect, possibly facilitated by breaking the task down into simple steps that could be applied in other patients, though some may need more time for teaching its use.

Several steps to assess conceptual understanding of the idea of conveying simple information about shoulder pain were devised. Firstly, determining the ability to indicate yes/no reliably and then to indicate recognition of the difference between pictures conveying shoulder pain and no pain. Some patients may be unable to progress further than indicating the presence or absence of pain in this way. However, using clinical training procedures over time to teach skills such as these has been shown to have a significant impact on the quality of care in patients with severe head injuries and can contribute towards resolving questions about their comfort, positioning and pain (Barreca et al., 2003).

Taking this one stage further, a reliable 'no' response to questions of whether pain is present under different circumstances would be expected to give rise to a rating of zero on the SPIN; that is pointing to the bottom white circle. Similarly, patients showing 'yes' would be expected to indicate a point between one and five. This presents another opportunity of establishing conceptual understanding of the SPIN.

Verifying that the patient can see the whole scale and point to each circle is also important, since the presence of hemineglect could erroneously indicate misunderstanding on the part of the patient when the problem is a visual one that could be solved by adjusting factors that affect vision. For example, presenting the SPIN in a different size, making sure that lighting is optimal and spending some time orientating them to the task might overcome this difficulty, but this requires testing in a larger cohort of patients with similar difficulties to the patients tested here.

Graham was able to point to each circle on the SPIN when the task was explained to him using gesture, but failed to understand what was being requested of him when he was asked to point to the largest, smallest and middle sized circle. Though this abstract task was impossible for him, it did not necessarily indicate an inability to associate the sensation of his pain with the visual SPIN in conjunction with pictures indicating pain. However, this raises doubts about the use of verbally administered pre-screening questions for patients with significant receptive dysphasia, because successful use of the SPIN could depend more on the ability to directly match the subjective experience of pain to a visual image suggestive of pain than on linguistic competence. This invites the question of how to test its validity and reliability.

The absence of a 'gold standard' pain intensity scale already validated for the stroke population makes testing concurrent validity implausible. However, one way of testing predictive validity could be to adapt the practice of cross modality matching, a widely used psychophysical method for validating pain intensity scales in experimental circumstances. This entails individuals matching known levels of one modality, for example, randomly applied stimuli of known intensity, to another modality, such as a numeric, verbal or visual analogue pain scale (Duncan et al., 1989; Price et al., 1994). Statistical evaluation of the stimulus-response relationship provides a measure of validity for the pain scale. This method has informed a validation study for the children's coloured analogue scale (CAS) (McGrath et al., 1996), in which children rated the sizes of seven circles varying in area using both a VAS and the CAS.

A different method was used by Price et al. (1999) to determine stroke patients' ability to use different kinds of pain scale and has since been successfully extended for use as a screening test in a longitudinal study to investigate the severity of upper limb pain after stroke (Price, 2003). A sphygmomanometer cuff tightness test was used to determine whether stroke patients could correctly indicate directional change of a stimulus. They recorded their impression of cuff tightness changes using several pain intensity scales; the purpose being to determine which scale best reflected their ability to self-report. Their understanding was assumed if they followed the sequence correctly and they then used their preferred scale to rate their upper limb pain. This method would commend itself for further testing of the SPIN in a larger cohort of patients. To further delineate the groups of patients for whom it may be most useful, additional tests of cognitive and language ability should be included.

It was a limitation of this study that test-retest reliability of the SPIN was not evaluated with Graham and this should be redressed in a further investigation. There could, though, be some difficulties with designing a study to evaluate test-retest in a population of patients who are likely to have memory deficits that could confound the rating of past pain, such as pain at night. Similarly, as found when testing the SPIN with a non-stroke population, and in a study evaluating the test-retest reliability of the AbilityQ and ShoulderQ, the lability of present pain can also confound reliable retesting of pain intensity (Turner-Stokes & Rusconi, 2003).

7.18 Conclusion

Whilst over half of the individuals who took part in the preliminary study to evaluate the SPIN commented on it in positive terms, the NRS was nevertheless preferred by the majority. This adds support to the view that the NRS should be the scale of choice for clinical and research purposes in general. Although no claims can be made that the SPIN is a better scale, this small case study does suggest that it may have a potential use in enabling some stroke patients, who are unable to self-report on their shoulder pain using either verbal or numeric scales, to do so. Taken together, the two parts of this study have laid the groundwork for further testing of an intuitive pain intensity scale that is worthy of development in the population for whom it was conceived.

Chapter 8

Discussion, recommendations and conclusion

8.1 Introduction

Reaching the end of this programme of research prompts a number of questions. First and foremost: What has been gained from it all? In answer, I would claim two benefits. From a personal perspective, designing and conducting a series of research projects from start to finish has contributed in no small measure to my professional development. From a much wider perspective, I believe that understanding of post-stroke shoulder pain and its assessment has been advanced. The overall achievement is an original contribution to knowledge, as evidenced by a series of findings.

8.2 Summary of findings

In summary, stroke patients' understanding of their shoulder pain develops in the light of their dependency and their care. They perceive it to be relieved or exacerbated by a range of psychological and contextual factors in addition to the physical factors generally known about. A number of patients strive to cope with the problem themselves and use a series of strategies to gain control over their predicament, whereas others adopt a more passive role. Some think that many health professionals are poorly informed about this condition and that communication about it is haphazard. Then again, it was found that health professionals are aware of shoulder pain to the extent that they can discern a range of behaviours that indicate it in patients with communication deficits. Moreover, some show great patience and sensitivity, using observation of patients' behaviour together with words and gestures, to confirm their suspicions about it, whereas others appear to question behavioural signs less.

These insights and others detailed in the text also show that determining the presence of shoulder pain and assessing it in stroke patients is a complex and imprecise process, which appears to depend on a number of factors. Some are specific to patients: Their actual ability to perceive pain, their inclination to conceal or mention their shoulder pain problem, their ability to convey information about it using meaningful language and/or gesture and the nature and clarity of the pain behaviours they express. Others are specific to health professionals: Their awareness that shoulder pain could be a problem for stroke patients, their sensitivity to signs suggestive of shoulder pain and the initiative they show in asking about these signs or exploring and verifying them. And there are also contextual issues, such as the type of ward patients are in, whether the multi-disciplinary team is well co-ordinated and whether a system is in place for prompting regular pain evaluation. Failure of any of these jeopardises successful communication about pain and generates misunderstanding.

Notwithstanding its complexity, there is an acknowledged need to capture some characteristics of post-stroke shoulder pain systematically in clinical settings, for example, its intensity, frequency and circumstances. However, the regular use of appropriate instruments to assess aspects such as these for the purpose of evaluating the efficacy of interventions and determining outcome appears to be almost non-existent. Even if they were widely available, patients do not necessarily find structured assessments easy to use and may have individual preferences. Moreover, patients with communication and cognitive deficits may need time and training before they can reliably report on shoulder pain themselves. Developing new scales designed with their needs in mind, such as the pictorial scale described here, may empower some to convey information more effectively.

To put these findings in context, Table 26 (page 217) outlines existing knowledge of post-stroke shoulder pain and its assessment and summarises the new information gained from this thesis.

Table 26:

Summary of what is already known and what this thesis adds to the subject

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What is already known

- Shoulder pain after stroke is thought to arise mainly from:
    - The primary physical changes that occur in and around the shoulder after a stroke
    - Secondary damage to soft tissues around the shoulder
    - Central lesions, for example in the thalamus
    - Careless lifting and handling (suggested by anecdotal evidence)
- There is little consistency in the assessments used to rate post-stroke shoulder pain
- Some pain rating scales are unsuitable for patients with deficits of cognition and communication

What this thesis adds

- Findings from a series of focus groups show that some stroke patients believe that:
    - Repeated injury to the shoulder occurring before nociception recovers contributes to pain
    - Shoulder pain is exacerbated by feelings of anxiety, depression, anger, fear and resentment
    - Some health professionals lack awareness of post-stroke shoulder pain
    - The regular assessment of shoulder pain is rare in hospital settings
- These findings also suggest that barriers to communication about shoulder pain come from:
    - Patients who conceal their pain or who feel inhibited about telling staff how to handle their arm
    - Staff who do not realise the need to ask about it
- Findings from a series of critical incident interviews with health professionals show that:
    - Discrete pain behaviours that indicate shoulder pain can be recognised in stroke patients
    - A range of different processes are used to verify behavioural signs of shoulder pain
    - Sensitivity to changes in pain intensity differs between health professionals
- Findings from a preliminary investigation into a pictorial pain intensity scale suggest that:
    - Patients vary in their preferences for pain intensity scales of different kinds
    - Stroke patients who are unable to use pain intensity scales in numeric or verbal format may respond to a pictorial scale given time and practice.

Before discussing the implications of these findings, the benefits and limitations of the overall approach used here will be addressed.

8.3 The overall approach

My approach to this research was influenced by theory and by clinical necessity. I was looking for answers to questions about how shoulder pain could best be assessed in stroke patients because a review of the scientific literature had revealed significant gaps in this area. Subsequent immersion in literature that I was previously unfamiliar with; that is the literature on pain and its assessment, highlighted the multi-dimensional nature of pain and guided the epistemological position I adopted and the methodological choices I made at each stage. In particular, the discovery of two connected theoretical models (Hadjistavropoulos & Craig, 2002; Prkachin & Craig, 1995) that explain pain expression as a complex process of social interaction, by which information about the experience of pain is encoded, detected and interpreted by another person, played a major part in determining the research agenda.

8.3.1 Benefits of the approach

There were advantages to using theory in this way. By deconstructing pain assessment, both models enabled it to be seen as a series of interconnected phases. This informed and clarified the purpose of the studies carried out, each one being grounded in a different phase of the overall process. Also highlighted in these models was the theoretical influence of groups of variables on each phase; for instance, the respective influence of extrinsic factors on nociception and observer bias on decoding pain behaviour. The findings of the studies reported here can now be located within the Model of Pain Communication (Hadjistavropoulos & Craig, 2002) and can thus be seen in the context of a logical framework. Taking this one step further, gaps in knowledge can be identified and the model can inform the design of studies to fill them.

The clinical dilemma that prompted this investigation also affected the methodological approaches used. There were compelling reasons to explore better ways of helping stroke patients to explain their shoulder pain to others in the context of everyday healthcare. However, this raised questions about their experiences of shoulder pain in general as well as questions about how this information could best be determined in patients with complex problems. These issues were poorly understood and not amenable to research using traditional quantitative methods. Thus the need to look afresh at this complicated problem took the research into a different realm of exploration. To unite these issues, the studies I designed had a common thread running through them, in that they were all carried out in clinical settings. Furthermore, though mixed methods were used, there was a strong emphasis on using qualitative methods to discern the real world of post-stroke shoulder pain and its assessment from the perspective of individuals directly involved. Taken together, the studies reveal different aspects of clinical reality.

Thus this broad and innovative approach, which has not been used before to research post-stroke shoulder pain, was underpinned by theory but explored in practice. Using theory in this way increases the academic merit of this clinically based thesis. The strength of the approach was that it generated rich and diverse contributions from both stroke patients in pain and health professionals with the responsibility of finding out about it. The use of qualitative methods was well suited to identifying issues of importance to both these groups. Furthermore, in acknowledging that stroke patients convey information about pain in different ways, it examined most known ways of doing this using both self-report and behavioural means. To have privileged one or two of these factors above others would have given an inadequate picture of the problem overall.

Keeping field notes throughout enabled me to take a reflexive view of progress at intervals throughout the programme of research. This helped me to be mindful of my own biases and informed the way the study findings were interpreted. To add to previous clinical experience, I gained information at first hand from thirty stroke patients with shoulder pain during this investigation. They ranged from those fully able to articulate their experiences to those with profound communication deficits, who conveyed information about pain by gesture and through their behaviour. I also interviewed thirty-four health professionals and had informal discussions with many others. This enabled me to be as inclusive as possible in analysing aspects of shoulder pain assessment, to remain open to the advantages and disadvantages of different assessment methods and to understand where these could be applied to best effect.

8.3.2 Limitations of the approach

One aim of qualitative research is to explore individual similarities and differences as a way of elucidating complex situations. It was a limitation that the patients who participated respectively in the focus group and critical incident studies were similar in more ways than they were different, in that the first cohort had intact verbal skills whereas the second did not. In neither did the participants reflect the true diversity of the stroke population as a whole, so the findings in each case were biased towards these respective cohorts. Similarly, though the health professionals interviewed included representatives of most groups who care directly for patients in hospital, there were no agency staff among them. Furthermore, no account was taken of stroke patients who are cared for outside hospital settings or who attend rehabilitation units as out-patients. An increasing proportion is now discharged to early supported care at home and others are cared for in nursing homes. As suggested by Wanklyn et al. (1996) and Ratnasabapathy et al. (2003), they may be particularly vulnerable to develop shoulder pain, which may not be well managed. These patients have, by and large, been neglected in the research literature and it is strongly recommended that their experiences of shoulder pain and its assessment should be investigated further.

It would have been informative to hold focus groups, or interviews, with other groups of stroke patients. For example, some with dysphasia might have been able to participate in supported focus groups as others have done (Kelson et al., 1999). But in this case, it would have been harder to justify using IPA as an analytical approach, as it is premised on finding out about abstract perceptions, such as how individuals make sense of their ill health, which would have been difficult for a dysphasic group to convey. Thus the benefits of diversity in sampling terms would have been outweighed by the drawback of not being able to use such an informative analytical method.

Likewise, behaviours displayed by patients included in the critical incident study should be regarded as specific to patients with communication deficits, as staff perceptions of signs of pain were only addressed in these patients. For example, staff might have paid particular attention to non-verbal patients' behaviour precisely because they knew that they could not convey information in any other way. Had more patients with intact verbal skills been included, different behaviours and processes of verifying them might have been revealed. In that case, the analysis could have been extended to compare the signs of pain that health professionals observe between groups who can and cannot self-report on pain.

An additional disadvantage to excluding some groups of patients in each case was that comparisons could not made between the two studies to explore the apparent difference between patients' perceptions of health professionals' awareness of shoulder pain and the awareness that health professionals themselves described having. This issue was raised again and again during the focus groups, which indicated that patients genuinely believed that health professionals had insufficient knowledge of shoulder pain. It would have been interesting to find out more about why they held this belief and the research agenda could have taken a different turn in pursuing this issue more extensively. For example, contemporaneous one-to-one interviews could have been carried out with stroke patients and the staff caring for them to explore these perceptions further and to find out how they came about. Alternatively, focus groups might have been held with health professionals to investigate their experiences of communicating about post-stroke shoulder pain, both with patients and other members of the multi-disciplinary team. Yet again, a questionnaire survey of health professionals might have reached a larger cohort and could yet prove to be a useful way of establishing the generalisability of the findings presented here.

Lastly, the decision to develop the SPIN necessitated a quantitative approach to determine its validity and reliability and this contrasts with the inductive approach used in the other two studies. However, the SPIN study also incorporated some qualitative components and furthermore, the final case study crossed the boundary between quantitative and qualitative research paradigms to some extent. I would defend this alternating use of mixed methods as essential to this kind of exploratory research, since the development of novel ways of enabling dysphasic patients to convey aspects of an elusive construct such as pain demands a degree of trial and error in real clinical settings.

Nevertheless, the SPIN could have been developed differently. Though the opinions of a few health professionals were sought during its design, the wider views of patients were not invited before it was tested with a non-stroke population and this is a limitation. On the one hand, its face validity could have been explored in this way before more detailed testing of its psychometric properties. But on the other hand, it was judged that the group for whom it was designed may need to learn how to use the scale before being able to judge its worth and that the views and opinions of the general population would reliably reflect its potential usefulness. It is recognised that development of the SPIN is incomplete and that further investigation is necessary.

8.4 Clinical and research implications

Turning to the clinical and research implications of these findings, four key issues merit discussion. Firstly, extending knowledge of post stroke shoulder pain as a multi-factorial problem, secondly, encouraging better communication about it in clinical settings, thirdly raising awareness of it through the education of health professionals and fourthly, determining how formal assessment should best be carried out.

8.4.1 Extending knowledge of post-stroke shoulder pain

As experts in their condition, I believe that stroke patients can make a valuable contribution to our understanding of shoulder pain and their insights into other pain related issues should be exploited in future research. Those who contributed here affirmed that post-stroke shoulder pain, in line with other painful conditions, has sensory and affective elements. Most described their pain intensity and its circumstances in explicit detail and were sure about what exacerbated and relieved it. They also cited affective elements, about which little has been documented before in this context; anger, annoyance, frustration, fear, resentment, anxiety and depression were all perceived to aggravate the experience of pain.

Clinical implications arise from the need to determine the influence these affective elements have on pain, because the psychological interventions or changes in care that could lessen them are different from interventions, such as analgesia or the use of arm supports, that are typically used to treat post-stroke shoulder pain. Moreover, as alluded to in some critical incident interviews, the behaviours displayed by, for instance, angry or frightened patients could confound the accurate interpretation of behaviours due to pain. Separately evaluating the sensory and affective components of pain could therefore lead to more comprehensive and more effective management. In particular, it is recommended that addressing fear and anxiety in relation to everyday physical activities should be part of routine care. This may prove to be difficult in some patients, but could be explored in others by health professionals directly asking about these aspects, or by using instruments appropriate to patients' understanding.

The research implications are that although some existing assessments may be accessible to stroke patients with good language skills, they should be carefully evaluated and others should be developed. A number, for example the self-report tool to measure fear-related pain behaviours developed by McCracken et al. (1992) is very long and uses sophisticated language. In addition, the value of the widely used McGill Pain Questionnaire (MPQ - reviewed on pages 49-50) is questionable. Though it includes both affective and sensory descriptors of pain, they differ from those described by patients here. This reinforces the findings of De Souza & Frank (2000), who concluded that individuals' condition specific descriptions of pain may be more relevant to therapeutic management than those rated using generic instruments such as the MPQ. Moreover, the purpose of MPQ affective descriptors, for instance sickening or frightful, is to indicate *what the pain feels like* as distinct from indicating how states such as anger or frustration, that are not included in this instrument, *affect the feeling of pain.*

An instrument worth investigating further is The Pain Discomfort Scale (Jensen et al., 1991). This has ten-items derived from statements made by patients with chronic pain. Respondents indicate feelings of annoyance, fear, helplessness and distress in response to pain on a five-point Likert scale. It is a valid and reliable measure of pain affect and offers a concise way of assessing a broad range of domains within this construct.

For patients unable to understand the language used in these scales, questions could be more simply worded and scored to enable them to self-report. For example, the four-point measure used by Partridge et al. (1990) to rate how much shoulder pain bothered patients (see page 17) could be extended to rate other aspects. Alternatively, a pictorial scale designed for aphasic patients that rates mood states including anger, frustration and depression (Brumfitt & Sheeran, 1999) could be used alongside the pictorial SPIN to prompt dialogue about affective factors associated with shoulder pain. The skills of a speech therapist or a psychologist with specialist experience in the field of stroke could be particularly beneficial here.

8.4.2 Communicating about pain in clinical settings

8.4.2.1 Informal interaction with nursing staff

Assessment using structured instruments can only go so far in capturing the information about pain needed to inform everyday management. Regular informal dialogue about pain and the daily observation of signs that suggest that a patient is in pain are equally important forms of assessment because if needed, patients can be given immediate help and reassurance, which can reduce pain and anxiety. This 'front line' role primarily falls to the staff who provide nursing care. Patients in the focus group study alleged that they were rarely asked about shoulder pain, adding support to assertions that pain in stroke patients is often not recognised and treated (The Intercollegiate Working Party for Stroke, 2000), and that clinical experience may increase the tendency for nurses to underestimate pain (Prkachin & Craig, 1995; Weiner et al., 1999). Moreover, several claimed that despite raising the subject with care staff, there was little to be gained from it and even that some doubted that there was much of problem at all.

Even allowing for the fact that some patients may have forgotten past conversations about shoulder pain, and that others may have concealed it for various reasons, the fact that so many believed that some staff looking after them were often unaware of the possibility they might be in pain indicated a problem needing attention. This conviction was reinforced by those who described having to explain to care staff exactly how to move them without causing pain; perceiving this as a further sign of their ignorance. Agency nurses were specially singled out as lacking this kind of specialised knowledge.

Comparing these views with findings from the critical incident study was interesting in that the nurses and care assistants interviewed did seem to be sensitive to signs of pain, although the majority acknowledged that judging its severity was difficult. However, being alert to signs of pain and doing something further about it by indicating to patients that it has been noticed are two different things. The importance that carers attach to expressions of pain and their reactions to it are said to be mediated by their personality and clinical or personal knowledge (Prkachin & Craig, 1995). This has implications for clinical practice, since whilst it is doubtful that much could be done to alter personality, a great deal could be done to enhance knowledge and to teach health professionals about the importance of showing they are aware of patients' shoulder pain. Even a few words could potentially eliminate one source of patients' distress – and would cost nothing.

8.4.2.2 Communication in therapy sessions

The part that physiotherapists and occupational therapists play in communicating about shoulder pain with stroke patients occurs in the context of their somewhat different professional role. This varies from that of nurses, who tend to have simultaneous responsibility for a number of patients with hands on contact mainly occurring during personal care activities, such as assisting with washing, dressing and transfers. In contrast, therapists' contact occurs during planned one-to-one sessions, during which specific activities designed to mobilise the upper limb or facilitate positioning are commonly undertaken (Pomeroy et al., 2001). Physical activity such as this is the hallmark of therapy and is seen by patients as offering the opportunity to recover the abilities that have been lost as a consequence of the stroke, enabling them to regain some control over their lives (Wiles et al., 2002). This may account for the belief held by patients in the focus group study that therapists had a better understanding of the physical causes of shoulder pain than nurses did. Hence they seemed more inclined to bear pain during therapy, seeing it as part and parcel of reversing the stiffness and immobility that troubled them and that prevented them from regaining that control.

While there is potential for communication about shoulder pain during therapy sessions, no published studies have been found that detail its nature or occurrence. However, the communication skills of therapists and the characteristics of their interaction with stroke patients have been explored more generally by researchers using qualitative methods. These studies tend to be small, which limits their generalisability, but their findings make an important contribution to understanding aspects of therapeutic interaction and showing how patient care could be improved.

Talvitie & Reunanen (2002) used discourse analysis to investigate how physiotherapy treatment interaction was constructed. Conversation was found to be somewhat one-sided, with therapists playing a dominant role and concentrating on physical issues, whereas patients were more passive, responding physically to instructions but not contributing in other ways. There also appeared to be little discussion of social or psychological issues. This focus on a biomedical discourse has also been found to pervade communication with other members of the multi-disciplinary team and to limit patients from voicing their concerns about rehabilitation (Bendz, 2000). Parry (2004) explored the procedures and reasoning that shape communication about goal-setting using conversation analysis. She also found that physiotherapists generally took the lead in initiating interaction, with patients' verbal contributions being limited. Yet again, others have found that while patients may value the general advice and information provided by physiotherapists, they may experience disappointment over the lack of discussion about aspects relating to the process of recovery (Wiles et al., 2002).

Taken together, these studies suggest that therapeutic interaction may concentrate on issues perceived to be important to professionals at the expense of other related problems that may be of equal concern for stroke patients, and that this inequity may be to their detriment. On the other hand, it has been argued that some patients collude in this unequal relationship by chooing to adopt a submissive role, thus showing their trust in the clinician as an authority figure who will deliver the treatment and information they need (Bendz, 2000; Parry, 2004). This debate goes some way to explain the dilemma expressed by patients in the focus group study (see page 116), who perceived themselves as dependent and expected therapeutic care from others with greater expertise, despite recognising the superiority of their own knowledge and understanding. It also highlights the need for health professionals to empower patients to communicate more openly about problems such as pain, in order to make sure they receive the most effective treatment.

8.4.2.3 The influence of context on interaction

The issue of informal interaction has ramifications that go beyond the skills of individual nurses and therapists. Over recent years, there has been a move towards the systematic management of stroke patients according to pre-determined processes of care within specialist stroke units. Such units are characterised firstly, by their focus on the rehabilitation team, whose co-ordinated approach has been shown to play a critical role in improving care and secondly, by a change from a largely biomedical approach to one that encompasses psychological and sociological aspects (Wade and de Jong, 2000). It is in this context that stroke patients with shoulder pain are now commonly managed and the efficacy of this philosophy of care in fostering communication about pain between individual team members and patients, as well as among the team, invites comment.

Despite stroke units incorporating a range of organisational practices designed to improve care, such as multidisciplinary meetings and intensive therapy input from specialist staff, Pound and Ebrahim (2000) hold that some intangible elements of care, including communication, may be less effective than they could be. By comparing three different models of stroke rehabilitation in a stroke unit, a general medical ward and an elderly care unit comprising acute and rehabilitation wards; they revealed some subtle but important deficiencies in stroke unit care. For instance, opportunities for interaction between rehabilitation nurses and patients were sometimes lost and this was attributed to a greater focus on functional and technical aspects of care in this setting, at the expense of a more holistic personal approach. In comparison, nurses on the elderly care unit were found to spend longer interacting with patients and questioning them while carrying out personal care activities. This difference in approach was inferred to arise in part from the upgrading of stroke unit nurses' professional status so as to equip them with the expertise needed to cope with the specialised techniques they are expected to use in these settings.

As well as influencing interaction initiated by nurses, the social context of care may inhibit patients' inclination to raise the subject of pain. As was shown in the findings presented here, though nurses were valued for the care they gave, some patients failed to mention that they had pain because they regarded the nursing staff as being too busy dealing with other more needy patients and preferred not to bother them. This paradox of nurses being seen as kind and attentive, albeit lacking the time to talk, has been found by others (MacDuff, 1998). It implies that failure to engage in 'everyday' communication about pain in clinical settings may be as much due to situational constraints as to the knowledge or attitudes held by staff.

8.4.2.4 Non-verbal communication

Turning to the non-verbal communication that was explored in the critical incident study, a somewhat different picture was painted, with staff coming over as both aware of and sensitive to behaviours suggestive of shoulder pain. It is possible that they became more attentive to these signs when they knew patients were unable to volunteer information for themselves. Different processes of verifying signs suggestive of pain were used by staff; some appeared to be particularly skilled at exploring behavioural cues further whereas others were less so. Unlike Marzinski (1991), who found senior nurses to be more perceptive towards pain than nursing assistants, no striking differences were noted from subjective examination of interview transcripts here. It was not possible to determine for certain whether professional differences or length of experience working with stroke patients had an effect on their capacity to observe and follow up behaviours indicative of shoulder pain. It would be helpful to explore this further.

Getting to know patients with severe communication deficits well was seen to be important, since building a close relationship with them and becoming familiar with their 'normal' demeanour enabled staff to become attuned to subtle changes in behaviour and was also used as a benchmark for determining pain. This corresponds with the findings of others that have explored pain assessment in patients with cognitive impairment. Both recognising change and clustering cues have been found to be crucial to reaching an understanding of pain in these groups (Donovan, 2002; Marzinski, 1991; Parke, 1998). This may be promoted if there is consistency in the care staff allocated to these patients, in which case discussing 'normal' behaviour alongside observed signs of pain behaviour could inform more valid team judgements about pain.

Previous research into pain behaviours has largely focused on their use as discrete indicators of pain outcome, as opposed to being part of an interactive process of communication along with speech and gesture. Much can be learnt from the strategies employed by the health professionals studied here, who gained knowledge from even the most profoundly impaired patients. The implications for both research and clinical practice are that these novel findings should be developed further to inform a logical method for investigating signs indicative of shoulder pain in stroke patients. This could form the basis for a teaching programme; possibly using videotaped interactions, to show staff how to assess shoulder pain in patients with communication deficits.

8.4.2.5 Interdisciplinary communication

Discussion between members of the healthcare team about shoulder pain was perceived by the patients studied here to be deficient, with some claiming that differences in knowledge between professional groups caused conflict. Similarly, few health professionals referred to sharing information about shoulder pain with others, though since this was not directly asked about in every critical incident interview, the true picture is unknown.

Exchanging information about signs of pain with other members of the healthcare team is essential, because behaviours may be ambiguous and interdisciplinary consultation can help in forming a consensus as to the presence and severity of pain. Furthermore, this may be the only way in which doctors, who spend less time with patients than other members of the team, are able to build up a picture of someone's pain as it fluctuates over time and with intervention. The lack of opportunity for establishing a relationship with stroke patients has been acknowledged by rehabilitation doctors and this, taken with their role as multi-disciplinary team leaders, can lead them to adopt a detached managerial role in which general solutions to problems prevail over individual ones

(Jones et al., 1997). In contrast, therapists and nurses tend to develop more participative relationships, assisted by the greater time they spend in close physical contact with patients.

In theory, collaboration between different members of the health care team during team meetings should be an opportunity for sharing information from these different perspectives. However, in their comparison of three settings, Pound and Ebrahim (2000) found there to be considerable variation in team communication. In one elderly care setting, some therapists found that information about a patient's emotional state was seen as irrelevant by a consultant who was more concerned with their mobility or function. This created tensions within the team and limited the opportunities for mutual discussion. Then again, a team on a stroke unit appeared to enjoy a more relaxed atmosphere in meetings, but though therapists played a more prominent role, nurses were more reticent.

It is recommended that further research should examine how team communication about post-stroke shoulder pain occurs, is documented and is integrated into clinical practice. Experience in developing the ICP in a rehabilitation setting showed that team discussion during the weekly ward round, or the fortnightly shoulder pain clinic set up to determine progress, ensured continuity of knowledge and provided a forum for seeing that documentation was kept up to date (Jackson et al., 2003). However, this system may not work in acute settings, where patients' stay may be measured in weeks rather than months and where systems for team communication could differ.

8.4.3 Raising awareness through education

Educating staff about post-stroke shoulder pain is not straightforward, since as a condition, it appears to 'fall through the net'. Stroke is a major health problem, frequently requiring life-saving intervention and attention to a range of complications. Education in stroke care tends to focus on these immediate problems and addresses primary clinical needs such as feeding and general immobility but even so, some registered nurses have been found to regard their undergraduate training as inadequate and to lack special education in stroke care (Kumlien & Axelsson, 2000). Moreover, staff on stroke wards have been found to lack both knowledge and competence in effective communication with patients (Kelson et al., 1999). A further difficulty arises from the fact that post-stroke shoulder pain is 'invisible' in comparison with other 'visible' secondary complications of stroke, such as contractures or pressure sores. This may account in part for the lack of attention it apparently receives but would support the need to raise its profile as a problem that should be actively looked for.

From a different viewpoint, though special services for patients with pain are widespread, they are concerned with conditions in which pain is a primary symptom. This is reflected in the pain literature and in the guidelines laid down for managing these conditions. They comprise acute pain of recent onset and short duration, as occurs after surgery or trauma; chronic pain, such as low back pain, which may persist beyond the expected time for healing or that occurs in degenerative conditions, and palliative care for patients with cancer pain. Again, post-stroke shoulder pain as a secondary problem falls through the net. Yet even if it were to be considered alongside these other conditions, a report by the Clinical Standards Advisory Group (CSAG) into services for patients in pain, which surveyed the training and education of health professionals specialising in pain management, found that:

> 'Education in pain management does not appear to be provided in a structured and coherent manner in many undergraduate courses for healthcare professionals.' (Clinical Standards Advisory Group, 1999)

Thus it would seem that undergraduate education in stroke care and pain management could be improved. It is important to address these topics at this level since two thirds of stroke patients spend most of their hospital stay on general wards (Rudd et al., 1999), where specific training in stroke management is unlikely to be routine. It is therefore recommended that pain assessment in the context of stroke should be a core topic in undergraduate education programmes for health professionals likely to have direct contact with stroke patients. This may need to be tailored to the needs of different professions, but should incorporate training to improve awareness of pain, to understand how communication deficits can affect information transfer and to enhance recognition and verification of pain behaviours in patients with these deficits. In addition, the selection and use of appropriate pain assessment instruments should be addressed. Lastly, in line with the specific CSAG recommendation that the multidimensional nature of pain should be emphasised in professional training, education about the emotional impact of shoulder pain and the importance of seeking information from stroke patients about other affective components, such as fear, should be included.

In terms of education in clinical settings, a proposal that staff knowledge of patients' needs could be supported by providing full training to all clinical staff involved in caring for stroke patients regardless of setting (Kelson et al., 1999) is strongly advocated. Such training has been shown to improve the handling skills of nurses and increase their social contact with patients (Forster et al., 1999). Training could occur through an induction programme for medical, therapy and nursing staff new to stroke care, which should reinforce existing knowledge by including information and training on shoulder pain assessment and management. Therapists with specialist training in lifting and handling could take the lead in teaching this aspect and nurses with specialist expertise in stroke care could take the lead in teaching interactive skills. Stroke patients themselves could also play a part in educating health professionals about these and other related issues.

8.4.4 Formal pain assessment

There is a move in the USA to make pain the 'fifth vital sign' to be looked for and evaluated in every patient (Palmer, 2002). However, patients and health professionals alike indicated that formal pain evaluation was the exception rather than the rule in the clinical settings they had knowledge of, though a few described scoring levels of pain intensity using a 0-10 scale or 'mild, moderate, severe', either by self-report or proxy. While it was recommended earlier (see page 30) that there should be agreement on a set of measures that provide the information needed to define different pain syndromes and to measure outcome, findings from the studies reported here can only make a tentative contribution to this debate. For now, three categories of pain assessment that reflect its principal purposes will be discussed. These comprise:

1. Determining the presence or absence of pain for case identification.
2. Establishing its salient characteristics to inform diagnosis and management.
3. Rating its severity to ascertain change over time and measure outcome.

8.4.4.1 Determining the presence of pain

In the context of a clinical examination, it is recommended that several methods be used for determining the presence of pain because relying solely on, for instance, analgesic use, spontaneous report of pain or a single rating of pain behaviour may underestimate the problem. Patients able to indicate yes/no reliably, using either verbal report or gesture, should firstly be asked if they have shoulder pain. This should be followed up by an enquiry as to whether it occurs at rest, on movement and at night. Pain at rest should be corroborated by palpation to identify tender areas around the shoulder and on movement, by passively elevating the arm and by testing lateral rotation of the shoulder. For patients unable to communicate, the only validated behavioural method is to rate pain behaviour during lateral rotation of the shoulder using the Ritchie Articular Index (RAI), though this uni-dimensional scale would miss pain that occurs in different circumstances. The recommendations for research are that a more comprehensive behavioural method should now be developed from the findings presented here.

However, even using measures such as these does not provide a foolproof way of finding out whether a patient has injured their shoulder. Not enough is understood about impairment of pain sensation after stroke. Though this does occur (Bassetti et al., 1993; Ploner et al., 1999), little is known about how many patients are affected and for how long. Some patients here described a period of sensory uncertainty after their stroke (discussed in section 5.9.4 on pages 120 and 121). They only realised later that injury could have occurred before pain perception had recovered. Thus assuming that a negative report of pain means that no injury has occurred may risk making a Type II error. The methodological implications are that looking for signs of injury early after stroke and then determining whether patients with these signs complain of pain, as has been done by some (Hakuno et al., 1984; Zorowitz et al. 1996), might give biased results. The corollary to this is that studies into the nature and causes of post-stroke shoulder pain should first identify a cohort of patients with pain in the shoulder or upper arm before considering other variables that may or may not be associated with it. Moreover, patients should be screened for their ability to rate pain reliably before inclusion in studies where pain intensity is a key measure of outcome.

The clinical implications are firstly, that all patients at risk of shoulder pain by virtue of their physical presentation, for example, those with reduced upper limb power (Price,

2004) or abnormalities of sensory input (Gamble et al., 2002), should be assessed at regular intervals to determine whether pain has developed. Secondly, even in the absence of reported pain, pain prevention strategies should be rigorously adhered to.

8.4.4.2 Characteristics of pain to inform diagnosis and management

No criteria have yet been defined to assist in the classification of different pain syndromes, except in the case of RSD and central pain. The lack of consensus as to what information should be sought should be addressed. Some distinct patterns noted by clinicians have been proposed (Davies, 2000; Ryerson & Levit, 1991; see page 30) but these have not been systematically researched. It was not possible to identify any generic patterns of pain from the small numbers of patients studied here. However, their ability to give insightful and detailed accounts of their pain experiences suggests that it would be useful to investigate the relationship between descriptions of shoulder pain and its physical presentation in a larger cohort of stroke patients. This could advance knowledge of causal mechanisms as well as assisting clinical reasoning.

Longitudinal studies are likely to be needed to elucidate common patterns of pain. For example, cohorts with distinct clinical presentations, such as subluxation or increased tone, could describe and document their symptoms regularly and systematically. Collated descriptions could then be examined for similarities and differences over time in the light of their changing physical condition.

8.4.4.3 Pain outcome measures

Though desirable to be able to recommend a 'gold standard' pain intensity measure for stroke patients, the heterogeneity of this population makes it impossible. It is undeniable that different patients need alternative measures because their conceptual understanding and ability varies. The focus group participants converged to the extent that they could all discriminate between levels of pain intensity, though their preference for measurement scales differed and some found certain scales confusing. This agreed with findings in the study carried out to validate the SPIN. In both studies, the VAS was favoured least. Taken alongside findings that others with cognitive impairment in general perform poorly when using both a traditional and sliding VASs (José Closs, Barr, Briggs, & Seers, 2004; Price et al., 1999), this scale cannot be recommended.

Neither can the Faces Pain Scale (see page 48), as it may reflect affective states such as anger.

Thus for rating pain intensity in clinical settings, the pragmatic solution is to offer patients a choice of verbal or numeric scales, as this is likely to optimise the validity of their pain ratings. However, it is recommended that their preferences should be explored first to establish the face validity of these different scales, and to see if their choice is affected by their stroke related impairments. The SPIN needs to be tested further as an alternative way of enabling stroke patients with poor understanding of both verbal and numeric scales to convey reliable information about their pain intensity. As increasing scale sensitivity reduces reliability (Price et al., 1999), scales using a 0-5 metric are recommended for less able patients and as there may be a learning effect with practice, some may need training in scale completion.

Defining 'cut-off' points for patients with impairments affecting their ability to self-report is problematic, as tests of cognitive function, such as the Hodkinson Mental Test used in the SPIN study, are inaccessible to patients with dysphasia. A start has been made with the AbilityQ, which has been found to be useful as a screening tool in that it can be assumed that patients who are unable to complete the simple questions posed are also unlikely to be able to complete the ShoulderQ. On the other hand, it is still unclear whether correct completion of the simple questions, in particular those involving word matching, is enough to support the validity of patients' responses to the more complex abstract questions about pain in the ShoulderQ. Further evaluation is needed and is in train. In the light of the best available evidence, though, and considering the findings reported here, it is suggested that patients be divided into three broad groups:

1. Patients who 'pass' the AbilityQ. This group can go on to complete the ShoulderQ (with assistance if necessary). Either verbal or numeric scores for pain at rest, at night and on movement should be recorded to reflect their self-reported pain intensity and supplementary information about the timing, frequency and context of their pain should also be obtained. If patients' responses are at variance with the clinical judgement of the multi-disciplinary team, further information may need to be sought to clarify the situation.

2. Patients who 'fail' the AbilityQ. They should be assisted to self-report using words or gestures as far as they are able to, initially using yes/no responses to simple questions. The pictorial SPIN offers an alternative approach to self-report that may enable some patients to convey information reliably. However, training in its use is likely to be needed.

3. Patients unable to self-report reliably. This group can only be assessed for pain through observation of their behaviour. There is as yet, no validated way of doing this other than by using the RAI, but watching facial expression during palpation and arm movement is likely to indicate its presence or absence.

There are research implications in connection with each of these suggested methods, some of which have been outlined. In particular, further development of a scale for rating shoulder pain behaviours is recommended. Suggested ways of doing this are firstly, through a survey to establish whether the behaviours detected and coded here reflect the observations of a larger group of health professionals. Alternatively, these behaviours could be compiled into a scale that could be tested in clinical settings.

In the light of the uncertainty that attends stroke patients' ability to reliably self-report on their pain, combining self-report of pain intensity with a behavioural report would deliver the most comprehensive information about shoulder pain in clinical settings. Both self-report and observational methods of assessment contribute unique information about someone's pain and the weighting given to the two may need to be varied, both between patients and within the same patient over time. However, it should be borne in mind that as the two rate different aspects of a patient's pain they should not be used interchangeably (Jackson, 2003).

8.7 Conclusion

The qualitative findings presented here reflect the experiences of a small number of stroke patients. While providing interesting insights, their experiences cannot be extrapolated to the general population of stroke patients admitted to hospital. Nevertheless, those who collaborated in this research played a crucial part in advancing our understanding of post-stroke shoulder pain through recounting their experiences of it. As experts, their insights into every aspect of it, from its initial recognition in hospital to the way some took on responsibility for teaching staff about it, emphasised its complexity. The apparent lack of concordance between pain and injury that was described should be taken into consideration when making assumptions about the causes of shoulder pain. In addition, greater attention ought to be paid to the impact of psychological and contextual factors on pain than has been the case to date.

The expertise shown by health professionals whose responsibility it is to be aware of signs of pain seemed to be variable with some having little knowledge of patients' shoulder pain and others showing great sensitivity and persistence in their efforts to evaluate it. There is a need to close this gap in knowledge by educating all health professionals about post-stroke shoulder pain and by encouraging open communication about it in clinical settings. There are also good reasons to develop better methods of assessing it in stroke patients who find self-report difficult, and to be prepared to spend time and patience teaching the use of such methods to maximise patients' autonomy.

Two patients described their experiences of good care as being a matter of luck and one told of a nurse who thought that stroke patients don't have pain. This implies that management of shoulder pain sometimes falls below an acceptable standard. It should be the right of every patient in hospital to be cared for with understanding and compassion. It is unacceptable to find that some of the distress experienced by patients with post-stroke shoulder pain could be due to the poor quality of their care. It adds insult to injury and demoralises patients at a time when they are at their most vulnerable. There is clearly much work to be done.

APPENDIX A

HARROW RESEARCH ETHICS COMMITTEE
(Chairman: Dr David Lubel)
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THE NORTH WEST LONDON HOSPITALS
NHS TRUST
WATFORD ROAD HARROW
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5 September 2001 COPY

Dr L Turner-Stokes
Consultant in Rehabilitation

Dear Dr Turner-Stokes

Ethics Submission No 2775: Repeatability of the Northwick Park AbilityQ and hemiplegic shoulder pain questionnaire in a cohort of stroke patients with severe complex disabilities

I am pleased to inform you that the extension of the above study as notified in Diana Jackson's letter of 30 July has been approved by Chairman's action.

Yours sincerely

Brian Saperia
Administrator

APPENDIX A

The North West London Hospitals NHS
NHS Trust

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Dr. David Lubel,
Chairman of Harrow Research Ethics Committee

July 30th, 2001

Dear Dr. Lubel,

Extension to Ethics Committee Submission No. 2775

I am writing to ask if you would be willing to grant Chairman's approval for an extension to the above study. To assist you in this, I am enclosing a completed application form for ethical approval, a patient information sheet, a consent form, and R & D project costing and registration forms.

This work stems from a project to develop a multi-disciplinary Integrated Care Pathway for the management of hemiplegic shoulder pain, which has been in progress on the Regional Rehabilitation Unit (RRU) at Northwick Park Hospital for the past two years.

One question raised by this project was how best to assess pain in stroke patients, many of whom find the pain assessments used in other conditions difficult to understand. To investigate this further, a study was carried out between October, 2000 and March, 2001 to evaluate two questionnaires (LREC ID 2775). Firstly, to screen stroke patients for their ability to answer some straightforward questions and secondly, to assess pain in patients deemed able to self report

About a third of our patients are unable to complete the pain questionnaire, so clinicians have to rely on their verbal accounts of pain, supplemented by information from the family or other staff members. The need now is to investigate the experiences of these patients and to find out how they describe their pain to members of the rehabilitation team. This is an essential prerequisite to developing a clinically relevant assessment tool for this group and as a first step, I would like to run up to three focus groups with patients from the RRU and the Stroke Unit at Northwick Park Hospital to explore their experiences and thus to increase our understanding of this problem.

I am in receipt of a fellowship from The Dunhill Medical Trust to fund this work as part of an MPhil/PhD degree at Southampton University. The University requires me to obtain ethical consent for all contributory studies. This one will involve minimal time for patients and is a development of the work which has already been approved. Moreover, there are resource implications associated with a full application to the Ethics Committee which this study may not warrant. I hope therefore, that you will be willing to consider granting approval by Chairman's action.

Yours sincerely,

Diana Jackson

(Mrs.) Diana Jackson
Research Physiotherapist, RRU

1/8/01

David

Can you approve this extension please.

KS

15/8/01

✓ OK

APPENDIX A

HARROW RESEARCH ETHICS COMMITTEE
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THE NORTH WEST LONDON HOSPITALS
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4 December 2000 COPY

Dr L Turner-Stokes
Consultant in Rehabilitation

Dear Dr Turner-Stokes

Ethics Submission No 2775: Repeatability of the Northwick Park AbilityQ and hemiplegic shoulder pain questionnaire in a cohort of stroke patients with severe complex disabilities

The above project was approved by the Harrow Research Ethics Committee at its meeting on 4 December 2000. It would be appreciated if, in any future correspondence relating to this project or in any entry made in case-notes about procedures undertaken in the course of this study, you would refer to it as **EC 2561.**

If this was a MREC approved project, consideration was restricted mainly to the suitability of the local researcher; the suitability of the site; the suitability of the subjects; and local aspects of the patient information sheet and consent form.

Set out overleaf is the REC membership list which should, if applicable, be copied to the sponsoring organisation.

General Practitioners should be kept informed of research work affecting their patients, particularly when the patient's involvement continues after discharge from hospital.

All adverse events arising during the course of this study should be notified, but please note that the Committee is only concerned to receive such notifications as they relate to subjects participating in trials in Harrow. Investigators undertaking trials on behalf of drug companies are asked to refrain from sending other adverse event reports, unless there are very exceptional circumstances.

The Committee operates according to GCP in most important respects.

Yours sincerely

Brian Saperia
Administrator

The North West London Hospitals NHS
NHS Trust

Northwick Park Hospital
Watford Road
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No: [ ]
Date: [ ]

Information sheet

Patients' experiences of shoulder pain after stroke

Principal investigator: Diana Jackson, Research Physiotherapist

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your doctor if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

The purpose of the study

Some patients develop pain in their affected shoulder after having a stroke. We need to find out more about this problem. One way of doing this is to ask patients to describe their experiences to us.

Why have I been chosen?

Because you have developed pain in your shoulder after having your stroke.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. You will be given a copy of this information sheet and the consent form to keep. If you change your mind later, you are still free to withdraw at any time without giving a reason. This will not affect the standard of care you receive.

What will happen if I take part?

You will be invited to join several other in-patients, who have also had shoulder pain after their stroke, to talk about their experiences in a group. The reason for getting a group together is that sometimes people remember things better when others are also discussing similar events.

The group will meet in the Day Room on the Stroke Unit at the most convenient time for everyone. We plan to meet for about an hour, but may go on for a little longer if people have a lot to say. You will only be asked to take part on one occasion and we will ensure that you don't miss any of your timetabled therapy sessions if you do take part.

Will my taking part in this group be kept confidential?
Only those people who take part in the group will know what has been talked about. We will ask you all not to disclose this information to others outside the group.

The two organisers of the group would like to tape record the conversation to make sure we don't forget anything you tell us about. The tape will be locked away. Some of the things you tell us may be reported to other medical staff, but only if this will benefit stroke patients who have shoulder pain. In this event, your real name will not be used.

Who has reviewed the study?
The Harrow Research Ethics Committee has reviewed the study.

Contact for Further Information
If you would like to ask any questions, or if you want more information so that you are absolutely clear what you are being asked to do, please ask me or another member of staff who knows you.

Thank you for reading this information sheet.

Diana Jackson,
Research Physiotherapist,
Regional Rehabilitation Unit,
Northwick Park Hospital,
Watford Road,
Harrow,
Middlesex,
HA1 3UJ

The North West London Hospitals NHS
NHS Trust

Northwick Park Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ

RESEARCH PROJECT CONSENT FORM

Hospital Number:

Name:

Date of Birth:

Title of Project: Patients' experiences of shoulder pain after stroke

Ethics Committee (EC) No: 2775 **Principal Investigator:** Mrs. Diana Jackson

PART A: TO BE COMPLETED BY THE INVESTIGATOR:

I confirm that I have explained this research project to the patient in terms which, in my judgement, are suited to the understanding of the patient and/or one of the parents or guardians of the patient.

Name of Researcher	*Signature*	*Date*
Name of Person taking consent (if different from researcher)	*Signature*	*Date*

PART B: TO BE COMPLETED BY THE PATIENT AND/OR PARENT OR GUARDIAN:

Please initial box

1. I confirm that I have read and understand the information sheet dated .... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that my identity will not be disclosed in any published or written data resulting from this study. ☐
4. I understand the above information and agree to take part in the above research project. ☐

Name of Patient (and/or Parent/Guardian)	*Signature*	*Date*

On completion, one copy of this form (the original) is to be inserted into the patient's case notes. A copy must also be handed to the patient to keep.

PATIENTS

- The researcher will explain the research study to you, and tell you what the possible risks and benefits of taking part in the research are.
- You can ask any questions and seek further information, so that you are absolutely clear what you are being asked to do.
- It is up to you to decide whether or not to take part in the research.
- If you decide to take part you are still free to withdraw from the study at any time without giving a reason. This will not affect the standard of treatment and care you receive.
- You may ask for a relative, or friend, or a nurse to be present.

Topic guide for focus group study

Topic: Stroke patients' experiences of shoulder pain

Purpose: To find out more about the problem of shoulder pain after a stroke and ways in which information about pain is exchanged between patients and hospital staff.

1. *Self-awareness of shoulder pain*

Opening question: When did you first realise that your shoulder was painful?

- What does it or did it feel like?
- How do you think it started in the first place?

2. *Others' awareness of your pain:*

Opening question: Who else knew about your shoulder pain when it started?

- How did they get to find out about it, for example, did anyone ask you if you had pain?
- What about the other people who were looking after you?
- What were your experiences of communicating about the pain with staff?
- How much did telling someone help?

3. *Improving care:*

Opening question: With your shoulder in mind, has your care differed between hospitals or wards?

- What about treatment for the shoulder pain?
- Has anything else happened to make the pain better or worse?
- How did you feel about this?
- What more could have been done?

4. *Impact of pain:*

Opening question: How much has the shoulder pain bothered you overall?

- Do you think it has affected your progress?
- If so, in what way?

5. *Using questionnaires/pain scales:*

Opening question: What are your views of using questionnaires or scales to describe pain?

- What do you think about these scales for rating pain intensity?
- Can you suggest any improvements?
- How could we make this easier for patients with language difficulties?

APPENDIX E

Winchester and Eastleigh
Healthcare NHS Trust

Royal Hampshire County Hospital
Rehabilitation Development Unit
Romsey Road, Winchester
Hampshire SO22 5DG

Tel: 01962 824940

../../

Dear...

A Study of Shoulder Problems after Stroke

I am writing to patients who have recently had a stroke to ask if you would be willing to take part in a research study.

The study is being conducted by Diana Jackson, who is a physiotherapist, and aims to increase our understanding of ways in which patients can most easily inform medical staff about the shoulder problems that affect some people after a stroke.

Enclosed with this letter is an information sheet telling you about the study and what will be involved if you agree to take part. After reading the information sheet, please tell a member of staff who knows you whether you would be willing to meet Diana Jackson to discuss this further. She will answer any questions you may have. After meeting her, you will have time to discuss this with anyone you wish before deciding whether to take part in the study.

It will make no difference to your medical care whether you take part or not. If you decide to take part, you will still be free to withdraw at any time without giving a reason and without affecting your usual medical care in any way.

Yours sincerely,

[Name]
Lead Consultant for Stroke

- Some patients may be invited to to take part in an additional study later on. If you are invited to, you will be given further information about this and will be able to decide whether you wish to participate or not.

Will this information be passed on to anyone else?
I will inform your medical team about the results of my assessment and will ask for their comments on any shoulder problems you have.

Otherwise, all the information I collect about you will be kept strictly confidential. I will not use your name or address on any of the records I keep. I will use a reference number instead.

What will happen to the results of the study?
When the study is over, I will write a report of my findings, which may be presented at a conference and published in a medical journal. This will be a summary of all the information collected. Individuals will not be identifiable from the report.

Who has reviewed the study?
The North and Mid Hampshire Research Ethics Committee has reviewed the study.

Contact for Further Information
If you would like to ask any questions, or if you want more information so that you are absolutely clear what you are being asked to do, please ask me - Diana Jackson - or another member of staff on the ward who knows you.

Thank you for reading this information sheet.

Winchester and Eastleigh
Healthcare NHS Trust

Royal Hampshire County Hospital
Rehabilitation Development Unit
Romsey Road, Winchester
Hampshire SO22 5DG

Tel: 01962 824940

Patient information sheet

A study of shoulder problems after stroke

Principal investigator:

Diana Jackson,
Research Physiotherapist
University of Southampton.

Tel: 023 8059 4645

Version 2, July 2002

Ethics Committee No: 144/B

APPENDIX F

APPENDIX F

Introduction

- You are being invited to take part in a research study.
- This sheet explains the purpose of the study and what you are being asked to do.
- Please take time to read the following information carefully and discuss it with friends, relatives and your doctor if you wish.
- Ask me, or another member of staff if there is anything that is not clear, or if you would like more information.
- Take time to decide whether or not you wish to take part.
- If you decide not to take part, it will not alter your treatment in any way.
- Thank you for reading this.

Background

You recently had a stroke, an interruption in the blood supply to part of the brain. This can cause weakness on one side of the body and as a result, some people go on to develop problems in their affected shoulder. Sometimes these problems cause pain.

Finding out about the shoulder problems that might cause pain can be difficult, because some patients can't easily explain what their shoulder feels like after a stroke.

Why is the study being done?

The aim of this study is to find out how patients describe the sensations they have in their affected shoulder. This will help us to recognise and understand their problems early on and give them the best treatment if they do develop pain. This research is being carried out as part of a PhD degree.

Why have I been chosen?

All stroke patients admitted to the Royal Hampshire County Hospital between September 1st and December 30th 2002, and who stay in hospital for more than two weeks, will be invited to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form.

You will be given a copy of this information sheet and the consent form to keep.

If you change your mind later, you are still free to withdraw at any time without giving a reason. This will not affect the standard of care you receive.

What will happen to me if I take part?

Two weeks after your stroke, I will arrange a convenient time to meet you for an assessment that will take about half an hour. The assessment can take place by your bedside or in a quiet room if you would prefer this.

- You will be asked some general questions and some more specific questions about your shoulder.
- I will examine your shoulder to find out about any problems you have. This will involve feeling for any tender areas you may have and carefully moving your shoulder to see if any movements cause discomfort.
- This assessment will be repeated every two weeks while you are in hospital because sometimes painful problems develop later on. If you are sure you don't have any pain and you are able to move your arm freely, I will not need to repeat the examination of your shoulder.

Winchester and Eastleigh NHS
Healthcare NHS Trust

Royal Hampshire County Hospital
Rehabilitation Development Unit
Romsey Road, Winchester
Hampshire SO22 5DG

Tel: 01962 824940

Ethics Committee No: 144/B

Patient identification No: ....

CONSENT FORM

Title of Project: A study of shoulder problems after stroke

Principal Investigator: Diana Jackson

Confirmation by researcher

I confirm that I have explained this research project to the patient and/or their family in terms which, in my judgement, are suited to their understanding.

____________________	____________________	____________________
Researcher	*Signature*	*Date*

Consent by patient

Please initial box

1. I confirm that I have read and understand the information sheet (version 2 July 2002) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that sections of any of my medical notes may be looked at by Diana Jackson where it is relevant to my taking part in research. I give permission for her to have access to my records. ☐
4. I agree to take part in the above study. ☐

____________________	____________________	____________________
Name of Patient	Signature	Date
____________________	____________________	____________________
Independent witness	Signature	Date

Assent by another person

Please initial box

1. I confirm that I have read and understand the information sheet (version 2, July 2002) for the above study and have had the opportunity to ask questions. ☐
2. I agree that .... may take part in the study and understand that he/she can withdraw from the study at any time, without having to give reasons and without it affecting their future medical care. ☐

____________________	____________________	____________________
Name of person giving assent	Signature	Date
____________________		
Relationship with patient		
____________________	____________________	____________________
Independent witness	Signature	Date

Ethical issues

Staff and the patients they describe will be allocated ID code numbers which will be used on all documentation and transcripts. The matters discussed will be confidential; you will be asked not to disclose any information to other people.

Sections of the transcript will be reproduced as part of a PhD thesis, with identities of the participants and settings anonymised. Taped data will be deleted on completion of the research.

Results of the study

When the study is over, I will feed the results back to staff at the RHCH. A report of my findings may be presented at a rehabilitation conference and published in a medical journal. This will be a summary of all the information collected. Individuals will not be identifiable from the report.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. You will be given a copy of this information sheet and the consent form to keep.

If you change your mind later, you are still free to withdraw at any time without giving a reason.

Who has reviewed the study?

The North and Mid Hampshire Research Ethics Committee has reviewed the study.

Contact for Further Information

If you would like to ask any questions, or if you want more information so that you are absolutely clear what you are being asked to do, please ask me - Diana Jackson.

Thank you for reading this information sheet.

Winchester and Eastleigh NHS
Healthcare NHS Trust

Royal Hampshire County Hospital
Rehabilitation Development Unit
Romsey Road, Winchester
Hampshire SO22 5DG

Tel: 01962 824940

Staff information sheet

Detecting shoulder pain in stroke patients

Principal investigator:
Diana Jackson,
Research Physiotherapist
University of Southampton.

Tel: 023 8059 4645

Version 2, July 2002

Ethics Committee No: 144/B

APPENDIX H

APPENDIX H

Background

Shoulder pain is a common and distressing complication of stroke which can limit use of the arm, delay recovery and prolong length of hospital stay. Its causes are not fully understood, but probably arise from changes associated with paralysis, such as altered muscle tone, prolonged immobility, postural malalignment and contractures.

Shoulder pain is difficult to assess in stroke patients, because some have sensory, cognitive and/or communication deficits and cannot easily tell other people what the problem is.

As a result, hospital staff caring for stroke patients sometimes have to rely on what patients are able to tell them using simple language or gestures, supplemented by their own observations and reports from other people.

Purpose of this study

The overall purpose is to inform the development of a shoulder pain assessment for stroke patients. This research is being carried out as part of a PhD degree. The aim of this particular part of the study is to investigate how health professionals detect the presence of shoulder pain in individual stroke patients.

Patient participants

All stroke patients admitted to the Royal Hampshire County Hospital between September 1st and December 30th 2002, and who stay in hospital for more than two weeks, will be invited to take part.

All those consenting, or for whom assent is given from a relative, will be screened by me for the presence of shoulder pain. This will be done two weeks after stroke onset and then at fortnightly intervals until discharge. Patients found to have shoulder pain will form the sample group for this study.

Staff participants

All members of staff having close contact with patients in this group will be invited to participate in an interview study. They will comprise health care assistants, nurses, physiotherapists, occupational therapists and doctors. Agency, locum, night and week-end staff will be included.

Procedure

Once patients have been identified as having shoulder pain, I will make contact with the key staff involved in their care and ask if they would be willing to take part in a short interview. Staff will be given time to consider their response. If they choose not to take part, no further questions will be asked.

Interviews will be brief and to the point, focusing on recall of specific incidents that inform staff that the patient has shoulder pain. A pilot study carried out with eight members of a rehabilitation team in another hospital showed that no interviews lasted more than sixteen minutes.

Staff will be asked for information about their professional group and their length of experience working with stroke patients. This will allow me to describe the group of participating staff when I write up the results of the study.

I am well aware that health professionals have very little spare time while they are on duty. Everyone will be consulted about the most appropriate timing of interviews and I will aim to be available at a time to suit participants.

With the consent of those who agree, I would like to tape-record the interviews. This will make analysing the results easier and will also allow a validity check to be made on the findings.

APPENDIX I

Ethics Committee No: 144/B
Staff identification No: ....

Winchester and Eastleigh NHS
Healthcare NHS Trust

Royal Hampshire County Hospital
Rehabilitation Development Unit
Romsey Road, Winchester
Hampshire SO22 5DG

Tel: 01962 824940

CONSENT FORM

Title of Project: Detecting shoulder pain in stroke patients

Principal Investigator: Diana Jackson

Please initial box

1. I confirm that I have read and understand the information sheet (version 2, July 2002) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐
3. I understand that the discussion will be tape recorded and I agree to this. ☐
4. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Researcher	Date	Signature

APPENDIX J

HAMPSHIRE AND ISLE OF WIGHT HEALTH AUTHORITY
NORTH AND MID HAMPSHIRE LOCAL RESEARCH ETHICS COMMITTEES
Temporary Address for Correspondence to Basingstoke Office:
Harness House
Aldermaston Road, Basingstoke
Hampshire RG24 9NB
Tel: 01256 312248 Fax: 01256 312299
Email: sandra.tapping@~~mail@nm-ha.nhs.uk~~ nhpct.nhs.uk
www.hants.gov.uk/nmhha/ethics.html

Chair of Biomedical Committee: *Mrs Jane Ogden-Swift*
Chair of Qualitative and Non-invasive Committee: *Rev'd Dr Rosemary Baker*
Ethics Committee Co-ordinator: *Mrs Sandra Tapping*

Our ref: SKT/mk/441B/L4519

19th July 2002

Mrs Diana Jackson
Department of Psychology
University of Southampton
Highfield
Southampton
SO17 1BJ

Dear Mrs Jackson

441/B - An investigation into patients' experience of post stroke shoulder pain and its detection

Decision - Approval

Thank you for your letter of 10th July 2002 which dealt with minor amendments. I am satisfied with your response and am empowered to grant you full approval.

I must emphasise that whilst the committee look at work on ethical grounds, it is up to the Trust to finally sanction the work, taking into account financial and other implications.

To comply with good practice a list of members at the June 2002 meeting is enclosed.

The committee wish you every success with the study. The following conditions apply to all approvals:

(a) that you notify the LREC immediately of any information received or of which you become aware which would cast doubt upon, or alter, any information contained in the original application, or a later amendment application, submitted to the LREC and/or which would raise questions about the safety and/or continued conduct of the research.

(b) you need to comply with the latest Data Protection Act and Caldicott Guardian issues.

(c) you need to comply throughout the conduct of the study, with good clinical research practice standards, including obtaining informed consent.

APPENDIX J

(d) you need to refer proposed amendments to the protocol to the LREC for further review and to obtain LREC approval thereto prior to implementation (except only in cases of emergency where the welfare of the subject is paramount).

(e) you must supply an annual summary of the progress of the research project and of the conclusion and outcome of the research project and inform the LREC should the research be discontinued.

(f) that satisfactory indemnity arrangements agreed with the Trust are in place before the study commences.

The committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials involving the participation of human subjects as they relate to the responsibilities, composition, function, operations and records of an independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997.

Yours sincerely

Nuri Pansari
Vice Chair – Qualitative and Non-invasive Committee

enc June meeting members
Maureen Larkin - RHCH

Northwick Park Ability to Complete a Questionnaire V 2.A 2002

Patient ID

Date / /

Can you read this question?

If you can, mark the 'Yes' box ☐ Yes ☐ No

Now please mark the 'No' box ☐ Yes ☐ No

Please mark the middle number on this scale	Please mark the biggest number on this scale	Please mark the smallest number on this scale
10	10	10
9	9	9
8	8	8
7	7	7
6	6	6
5	5	5
4	4	4
3	3	3
2	2	2
1	1	1
0	0	0

Please indicate "mild" below:

☐ None
☐ Mild
☐ Moderate
☐ Severe

Please indicate "much worse" below:

☐ A lot better
☐ A little better
☐ The same
☐ Worse
☐ Much worse

Questionnaire completed: **By patient alone** ☐ **With help as scribe** ☐ **Reading questions out** ☐

Northwick Park Shoulder Pain Questionnaire V 2.A 2002 Page 1

Patient ID

Date / /

Do you have pain in your shoulder?

☐ Yes

☐ No

If yes, when do you have shoulder pain?

☐ All of the time

☐ Most of the time

☐ Some of the time

☐ Only when my arm is moved

How severe is your shoulder pain overall?

☐ Extremely severe

☐ Severe

☐ Moderate

☐ Mild

How do you rate your pain severity this week in comparison to last week?

☐ Much better

☐ A little better

☐ The same

☐ A bit worse

☐ Much worse

Does your pain wake you from sleep at night?

☐ Most nights

☐ Some nights

☐ Not at all

If it wakes you from sleep, how many times a night?

☐ More than twice a night

☐ Once or twice a night

☐ Only occasionally

Does your pain interfere with therapy sessions?

☐ Most sessions

☐ Some sessions

☐ Not at all

If it does interfere with therapy, how much?

☐ Very much

☐ Quite a lot

☐ Only occasionally

Northwick Park Shoulder Pain Questionnaire V 2.A 2002 Page 2

Mark the number that shows how severe your shoulder pain is at rest	Mark the number that shows how severe your shoulder pain is on movement	Mark the number that shows how severe your shoulder pain is at night
10	10	10
9	9	9
8	8	8
7	7	7
6	6	6
5	5	5
4	4	4
3	3	3
2	2	2
1	1	1
0	0	0

During which of the following do you have increased pain?

☐ Transfers
☐ Washing and dressing
☐ Physiotherapy sessions
☐ Turning in bed at night
☐ None of these

Which of the following helps to relieve your pain?

☐ Positioning, such as a pillow
☐ Pain-killing tablets
☐ An arm splint
☐ None of the above

What else makes the pain worse?

What else makes the pain better?

Thank you for completing this questionnaire

APPENDIX M

The Ritchie Articular Index

The Ritchie Articular Index grades joint tenderness using a four-point scale.

0 = Patient has no tenderness
1 = Patient complains of pain
2 = Patient complains of pain and winces
3 = Patient complains of pain, winces and withdraws

This scale has been applied to patients with post-stroke shoulder pain using the following method (Bohannon and LeFort, 1986).

Patients are positioned in supine with their entire body supported. Their affected arm is abducted to about 30 degrees. The elbow is maintained at 90 degrees with the forearm in neutral supination. The examiner stabilises the shoulder with one hand while using the other to slowly externally rotate the patient's affected shoulder.

The patient is observed during the procedure and asked afterwards if the movement caused pain. The rating is based on the observed behaviour of the patient and their response to the question. If the patient rolls towards the affected shoulder to reduce the stress on it during testing, the patient is judged to be withdrawing.

APPENDIX N

SOUTHAMPTON & SOUTH WEST HANTS
LOCAL RESEARCH ETHICS COMMITTEE

Chairman: Dr Audrey Kermode

Administrator: Mrs Clair Wright
Trust Management Offices
Mailpoint 18
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD

Tel: (023) 8079 4912
Fax: (023) 8079 8678

Ref: CPW/DBL

20 March 2001

Mrs D Jackson
Dept of Psychology
University of Southampton
Highfield
Southampton

Dear Mrs Jackson

Submission No:043/01 – Preliminary evaluation of a scale designed for rating pain intensity in stroke patients with shoulder pain.

Following the conditional approval and in response to your letter dated 13th March 2001, I am pleased to confirm **full approval** having clarified the committees concerns as detailed in your letter and receiving copies of the amended Patient Information Sheet and Consent Form now on headed paper.

This approval was granted by the Chairman Dr Audrey Kermode, the Committee will be notified of this action at their meeting in April.

This committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials involving the participation of human subjects as they relate to the responsibilities, composition, function, operations and records of an independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997.

Yours sincerely,

CMWright

Mrs Clair Wright
Research Ethics Manager

APPENDIX O

Hodkinson Mental Test

Score one point for each question answered correctly

Score	Question
________	Age of patient
________	Time (to nearest hour)
________	Address given for recall at end of test: 42 West Street
________	Name of hospital
________	Year
________	Date of birth of patient
________	Month
________	Years of First World War
________	Name of monarch
________	Count backwards from 20 - 1

APPENDIX P

Functional Limitations Profile

Each question refers to your function today, and refers to limitations arising due to your health.

Score	Tick if true	Question/statement
_____	_____	I make difficult movements with help; for example, getting in and out of the bath or a car
_____	_____	I do not get in and out of bed or chairs without the help of a person or mechanical aid
_____	_____	I only stand for short periods of time
_____	_____	I do not keep my balance
_____	_____	I move my hands or fingers with some difficulty or limitation
_____	_____	I only stand up with someone's help
_____	_____	I kneel, stoop or bend down only by holding on to something
_____	_____	I am in a restricted position all the time
_____	_____	I am very clumsy
_____	_____	I get in and out of bed or chairs by grasping something for support or using a stick or frame
_____	_____	I stay lying down most of the time
_____	_____	I change position frequently
_____	_____	I hold on to something to move myself around in bed
_____	_____	I do not bathe myself completely; for example, I need help with bathing
_____	_____	I do not bathe myself at all but am bathed by someone else
_____	_____	I use the bedpan with help

Functional Limitations Profile

Interview instructions (spoken)

I want to talk to you about the things you normally do every day.

I am going to read out some statements which describe things people often do when they are not well. Even if you think you are well, some of these statements may stand out, because they describe you and are related to your health.

Listen to each statement, think of yourself *today* and tell me if it describes you or not. For example, I might read the statement, 'I only stand up with someone's help'. If you have had help with standing due to your health and are still having help today, you should respond 'agree'.

Ask me to repeat a statement or slow down if you do not understand. Remember I am interested in both recent or longstanding changes in your health.

Self-administered questionnaire instructions

I am interested in the activities that you do in carrying on your life and any changes that describe you today that are related to your health.

This sheet lists statements that describe things people often do when they are not well. Even if you think you are well, some of these statements may stand out, because they describe you and are related to your health.

As you read each statement in the questionnaire, think of yourself today. When you read a statement that describes you and is related to your health, place a tick on the line to the left of the statement.

Queries that may arise

I've never been able to do that
Yes, I do want to know about things you have never been able to do

I've not been able to do that for some time.
I want to know about all recent or long-standing changes in the things you do.

Some days I can do that, some days I can't.
Think of yourself *today.*

It's due to my age.
Would you say that was due to your *health* or not?

None of this applies to me; I'm perfectly healthy.
A few of the statements may apply to you. It is therefore important that I do check them all, since I am comparing healthy people with less healthy people.

Southampton
University
Hospitals
Trust

The Chronic Pain Management Unit
The Royal South Hants Hospital
Brintons Terrace, Off St. Mary's Road, Southampton, SO14 OYG
Telephone Switchboard: 023 8063 4288

For appointments and general enquiries
Please telephone direct on 023 8082 5750
(24 hour answering machine service)

Chronic Pain Nurse Helpline
Please telephone direct on 023 8082 5064
(24 hour answering machine service)

Date ……….

Dear

We are writing to patients due to attend the pain management clinic to ask if you would be willing to take part in a research study. The study is being conducted by Diana Jackson and aims to increase our understanding of ways in which patients can most easily inform medical staff about the pain they experience.

Enclosed with this letter is an information sheet telling you all about the study and what will be involved if you agree to take part. After reading the information sheet, please use the enclosed form to tell us whether you would be willing to take part in this study, and return it in the prepaid envelope.

It will make no difference to your medical care whether you take part or not. If you decide to take part, you will still be free to withdraw at any time without giving a reason and without affecting your usual medical care in any way.

If you would like some more information, please contact Diana Jackson, telephone number 023 8059 4645.

Yours sincerely,

[Name]
Lead Consultant for Chronic Pain

APPENDIX R

University
of Southampton

**Department of
Psychology**

*University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom*

Telephone: 02380 594645
E-mail: D.M.Jackson@soton.ac.uk

Ethics Committee Submission No: 043/01
Centre Number: [ ]
Patient Identification Number: [ ]

Information Sheet

An investigation into ways of recording pain

Principal investigator: Diana Jackson, Research Physiotherapist

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your doctor if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

The purpose of the study

We need to find out more about how patients can most easily tell us about the pain they experience so that we can find out which treatments are most effective in certain conditions. The aim of this research study is to test several different ways of recording pain. We are therefore asking people who have medical conditions which cause them pain to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You will also be given a copy of the consent form to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

What will happen to me if I take part?

If you take part you will be asked to indicate some aspects of the pain you have by completing several different measurement scales. You will also be asked some general questions and for some information about your health related difficulties.

How long will this take?

To allow time for completing the scales and answering questions, and to ensure that you have finished in good time for your clinic appointment, you will need to arrive one hour before the appointment time. You will only be needed once for this study and you will be reimbursed for any extra car parking costs involved on that occasion.

What are the benefits of taking part?

The information we get from this study may help us to understand more about recording pain and therefore to treat future patients with certain kinds of pain more effectively.

What will happen to the information I give?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

Who has reviewed the study?

The Southampton and South West Hants Joint Local Research Ethics Committee has reviewed this study.

If you would like to take part in this research study, please could you complete and return the slip attached in the enclosed pre-paid envelope. I will then write to you to confirm the time I would like you to arrive and will answer any questions you may have.

Thank you for reading this information sheet.

Diana Jackson,
Research Physiotherapist,
Department of Psychology,
Southampton University,
Highfield,
Southampton,
Hants. SO17 1BJ

Telephone: 023 8059 4645

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Ethics Committee Submission Number: 043/01

Reply slip

An investigation into ways of recording pain

Diana Jackson, Research Physiotherapist
Department of Psychology
Southampton University

Name (capitals please) ....

I would / I would not *

be willing to take part in the research investigating ways of recording pain.

Signed ....

*** Please cross out which does not apply**

APPENDIX T

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Telephone: 02380 594645
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Ethics Committee Submission No: 043/01

CONSENT FORM

An investigation into ways of recording pain

Diana Jackson, Research Physiotherapist
Department of Psychology
Southampton University

Please initial box

1. I confirm that I have read and understand the information sheet dated .... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that sections of any of my medical notes may be looked at by the researcher conducting this study where it is relevant to my taking part in research. I give permission for this individual to have access to my records. ☐
4. I agree to take part in the above study. ☐

Name of Patient	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

APPENDIX U

Information sheet

Regional Rehabilitation Unit
Northwick Park Hospital

What is this about?

After a stroke, some people have pain around the shoulder.

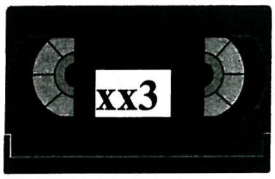
We need to find out more about this problem so we can make sure that patients are getting the best treatment.

We want you to tell us about your shoulder pain and how bad it is using some pictures and a new scale.

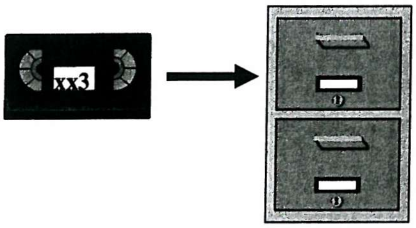
What will happen?

Your speech therapist will explain the pictures and the scale to you and help you to understand them.

We would like to tape record the session because this will help us to remember what was said.



What will happen to the tapes?



They will be locked away.

Your name will not be used and the information will be confidential.

Do I have to do this?

No, it's your choice.

If you change your mind you can stop when you want to.

APPENDIX V

Regional Rehabilitation Unit
Northwick Park Hospital

Patient Consent Form

Hospital Number:

Name:

Date of Birth:

Title of Project: Assessment of shoulder pain after stroke

Researcher: Diana Jackson

Please mark ☑ **Yes** or ☒ **No**

The study has been explained to me by Diana Jackson and I have had time to think and ask questions about it

☐ **Yes** ☐ **No**

I agree that the session will be tape recorded

☐ **Yes** ☐ **No**

I understand that all information is CONFIDENTIAL

☐ **Yes** ☐ **No**

If I change my mind I understand the session will stop

☐ **Yes** ☐ **No**

I agree to take part in this study

☐ **Yes** ☐ **No**

Name .... Signed ....

Witnessed by .... Date ....

CONFIRMATION OF CONSENT

Hospital Number:
Name:
Date of Birth:

Title of Study: Assessment of shoulder pain after stroke

Principal Researcher: Diana Jackson

TO BE COMPLETED BY THE RESEARCHER:

I confirm that I have explained this study to the patient named below in terms which, in my judgement, are suited to the understanding of the patient.

____

Name of Patient

_______________________	_______________________	_______________________
Name of Researcher	*Signature*	*Date*
_______________________	_______________________	_______________________
Name of Person confirming patient's understanding	*Signature*	*Profession*
		_______________________
		Date

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